MILLS & REEVE

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Personal Health Budgets for NHS Continuing Healthcare and Children's Continuing Care: A Basic Guide

The "right to request" a personal health budget was accorded to individuals entitled to NHS Continuing Healthcare and the healthcare element of Children's Continuing Care on 1 April 2014. A few short months later, this has become the much-trailed "right to receive". In this briefing we look at the basis of the personal health budget and, in particular, the legal framework surrounding direct payments.

What is a personal health budget?

A personal health budget (PHB) is an allocation of NHS money to an individual (or their representative or nominee) with an identified health need, in order that they can purchase services they believe will enable them to meet specific goals in terms of health and wellbeing. A personal health budget is centred on a support or care plan which identifies the person's health needs, the amount of money available to meet those needs and how that money is going to be spent to seek to achieve the desired outcomes. It is intended that the individual should be able to do this in ways and at times that make most sense to them, having agreed with the commissioner the goals that might be achieved. A PHB is outcomes-focused rather than dictated, in a more conventional commissioning model, by the service user's medical condition(s).

There are three types of PHB:

- A notional budget.
- A third party, real or nominee budget.
- A direct payment.

A notional budget remains in the hands of the commissioner but the individual's views on how the money should be spent are taken into account when services are commissioned for them. A third party, real or nominee budget is held by a third party (ie: neither service user nor commissioner), who enters into contracts with service providers for the patient's benefit. An Independent User Trust would be one possible model of third party budget.

What is the purpose of a PHB?

The idea behind the roll out of PHBs is to give people more control over how their needs are met, what services they receive and who delivers them. The PHB is intended to be a more creative device for care planning than we are perhaps accustomed to. CCGs and NHS England are under a duty to publicise and promote the availability of PHBs to eligible persons and their families and carers and to provide them with information, advice and other support to assist them in deciding whether to request a PHB. It will be interesting to see what proportion of individuals with extremely complex combinations of medical conditions, eligible for NHS Continuing Healthcare, for example, will wish to take up this offer of greater control over the shape of their care packages.

Key deadlines with respect to CHC and PHBs

1 April 2014 heralded the "right to request" a PHB for NHS Continuing Healthcare. In fact, many people had been requesting and receiving a non-direct payment type of PHB well before this date and, in so far as no one can stop a person making a request, the idea of a "right" to do so seems rather superfluous. On 1 October 2014, though, this so-called "right to request" a PHB became the much trailed "right to receive".

Part 6A of the NHS Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 (as amended) sets out, fairly briefly, the standing rules relating to personal health budgets and commissioners need to be familiar with these.

Regulation 32A defines a PHB as:

> "an amount of money (a) which is identified by a relevant body [ie: a CCG or NHS England] as appropriate for the purpose of securing the provision to a person of all or part of a relevant health service [ie: Continuing Care for Children (CCC) or NHS Continuing Healthcare (CHC)]; and (b) the application of which is planned and agreed between the relevant body and the eligible person or their representative".

"Representative" in this sense means such persons as the relevant body considers it appropriate to consult about, and involve in, a decision about a PHB for a particular individual eg: family members and carers[1].

Regulation 32B provides that a relevant body must ensure that it is able to arrange for the provision of CCC or CHC to an eligible person by means of a PHB managed as a direct payment and/or a notional budget and/or a third party budget.

Critically, regulation 32B(4) provides that, where a request for a PHB is made, a relevant body **must grant that request, save to the extent that it is not appropriate** to secure provision of all or any part of the CHC package (or of the health element of a CCC package) by means of a PHB in the particular circumstances of the individual's case.

However, it is not for the service user to stipulate the mode of delivery of the PHB. Regulation 32B(4A) provides that **where a relevant body accedes to the request for a PHB, it must decide which of the modes of delivery would be the most appropriate way in which to manage that PHB.** The service user can ask for this decision to be reviewed and may provide additional information to be considered as part of the review.

The relevant body must make provision for individuals for whom a PHB has been arranged, and their representatives, to obtain information, advice and other support relating to the management of the PHB. However, if a relevant body refuses to accede to a request for a PHB, it must provide written reasons for its refusal, and the

[1] NB: This is broader than the definition of 'representative' for the purpose of the direct payment regulations.

service user or their representative can ask for a review of that decision, providing additional material if wished, though no more than one review need be undertaken in any six month period.

This briefing continues with the focus predominantly on direct payments, the latest type of PHB to become available for healthcare. In the remainder of this briefing, "health body" is used to refer to a CCG, NHS England or a local authority exercising its public health functions.

What is a direct payment not intended to cover?

There are aspects of NHS care that are not intended to be covered by a PHB, including (but not limited to) primary care services, emergency services, vaccinations and pharmaceuticals. Moreover, under the National Health Service (Direct Payments) Regulations 2013 (the regulations), a direct payment (DP) cannot be made to a child (ie: someone under the age of 16), nor to various categories of person (including offenders released on licence) subject to drug rehabilitation/treatment/testing or alcohol treatment programmes. Services that consist of the supply or procurement of alcohol or tobacco, the provison of gambling services or facilities, or the repayment of a debt otherwise than in respect of a service specified in the care plan, are also excluded.

Who may, potentially, receive a direct payment?

Broadly, there are three categories of person to whom a payment can be made, either in their own right or as a representative of another:

- **A person aged 16 or over who has capacity to consent to the making of a DP to them** (and does so consent) and is not an excluded person described in the Schedule to the regulations, where that person is someone for whose benefit anything may or must be provided or arranged by a health body under the 2006 Act or, in the case of a CCG or NHS England, under any other enactment (eg: s117 Mental Health Act 1983).

- **A representative of a person under 16 (a child) for whose benefit anything may or must be provided or arranged by a health body under the 2006 Act or, in the case of a CCG or NHS England, under any other enactment**, and who is not excluded by the Schedule to the regulations. When the patient reaches 16, if both patient and representative or nominee (see below) consent, the health body may continue to make DPs to the representative or nominee in accordance with the care plan. If the patient does not consent to the arrangement continuing, the health body must stop making the DPs and must review the making of the DPs as soon as reasonably possible.

- **A representative of a person, other than a child, who lacks capacity to consent to the making of a DP to them**, who is not excluded by the Schedule to the regulations and for whose benefit anything may or must be provided under the 2006 Act or, in the case of a CCG or NHS England, under any other enactment. [NB: Where a person, other than a child, lacks such capacity but has no representative, the commissioner may appoint an appropriate person to receive and manage a DP on behalf of the incapacitous person]. Where an individual suffers what is likely to be only a temporary loss of capacity to consent to the making of a DP to them, a health body may continue to make DPs in respect of them if there is a representative or nominee agreeable to receiving DPs on behalf of the patient and the DPs are made subject to the condition that the patient is allowed to manage the DPs themselves for any period when the health body is satisfied that the patient has regained capacity and is able to manage the payment. When the patient gains or regains capacity to the making of a DP to them, if patient and representative or nominee both agree, the health body may continue to make DPs to the representative or nominee in accordance with the care plan. If the patient does not consent to that arrangement continuing, the health body

must stop making the DPs and must review the making of the DPs as soon as reasonably possible.

When is a DP appropriate?

In deciding whether a DP should be made to an adult with capacity, or in respect of a child or person without capacity, the commissioner must have regard to:

- Whether a DP is appropriate for a person with that person's condition.
- The impact of that condition on that person's life.
- Whether a DP represents value for money.

What must a representative of a child or person without capacity do?

A representative of a child or person without capacity, as set out above, must:

- Agree to act on the patient's behalf in relation to the DP.
- Act in the best interests of the patient when securing the provision of services in respect of which the DP is made.
- Be responsible as a principal for all contractual arrangements entered into for the benefit of the patient and secured by means of the DP.
- Use the DP in accordance with the care plan.
- Comply with the relevant provisions of the regulations.

What is a nominee and what do they do?

Another person – a "nominee" – may be nominated to receive a DP on a patient's behalf by:

- A patient aged 16 or over with capacity to consent to the making of a DP.
- A patient who, prior to losing capacity, has indicated a wish to have another person nominated to received DPs on their behalf should they lose capacity.
- The representative of a patient under 16 or the representative of a patient who is 16 or over and lacks capacity.
- A health body (where a patient loses capacity temporarily and a health body can nominate a person agreeable to receive the DP on behalf of the patient).

Before a DP is made to a nominee, the nominee must agree to receive the DP in respect of the patient and the health body must agree to making the DP to the nominee.

The nominee must:

- **Be responsible as principal for all contractual arrangements entered into for the benefit of the patient and secured by means of the DP**.

- Use the DP in accordance with the care plan.
- Comply with the relevant provisions of the regulations.

If the person who nominated the nominee notifies the health body in writing that they wish to withdraw or change the nomination, the health body must consider whether to stop making the DPs and must review the making of the DPs as soon as reasonably possible.

How does it work?

Any decision with regard to the making of a DP must be taken in accordance with the regulations, with which commissioners must familiarise themselves. Although CCGs may delegate the administration of DPs for healthcare to a third party, such as the local authority or CSU, CCGs must retain overall responsibility and remain legally responsible for all decisions made under the regulations.

Making a DP to a patient

The regulations list a wealth of factors to be taken into consideration before a health body decides whether to make a DP to a patient. It may consult with anyone identified by the patient, (if the patient is aged between 16 and 17) anyone with parental responsibility for the patient, carers, an IMHA/IMCA, any LA social care team and anyone else who may be able to provide relevant information. It may require the patient to provide information about their state of health, medical condition in respect of which a DP is sought and bank/building society, etc, account into which a DP might be made. The health body must be satisfied that the patient is capable of managing a DP by themselves or with the assistance that may be available to them.

Making a DP to a representative

In deciding whether to make a DP to a patient's representative, the health body may consult the patient, any court-appointed deputy, any donee of a lasting power of attorney, and anyone the patient (when they had capacity) may have suggested for the purpose, in addition to anyone listed above. The representative may be required to provide bank etc account information and the health body must be satisfied that the representative is capable of managing a DP by themselves or with the assistance that may be available to them. Account may also be taken of any wishes about DPs expressed by the patient when they had capacity and any views they may have held generally which would be pertinent.

Making a DP to a nominee

Similar considerations may influence the decision whether or not to make a DP to a nominee but, where a nominee is involved, the health body will generally require an enhanced DBS check (including suitability information relating to vulnerable adults) **unless** the nominee is an individual living in the same household as the patient, a family member within regulation 7(8) or a friend involved in the provision of the patient's care.

Is the recipient of the monies capable of managing a DP?

In deciding whether a patient, representative or nominee is capable of managing a DP, a health body may consider, in particular, whether the patient/representative/nominee would be a suitable person to arrange with any person or body to provide the services secured by the DPs, whether the patient/representative/nominee has previously been unable to manage a social care DP and whether the patient/representative/nominee is capable of taking all reasonable steps to prevent fraudulent use of the DP.

Refusing a DP

If a decision is taken not to make a PHB available to or in respect of an individual by means of a DP, the health body must give written reasons for its decision. A patient/representative/nominee may ask for reconsideration (and

may provide additional information for the purpose) but the health body need not undertake more than one such reconsideration within any six month period.

The process in outline

The first step in the process is to assess the patient, decide if a DP is appropriate and obtain a clear understanding of their needs. An approximate cash value of the PHB to which that person is entitled should then be identified; this is the "indicative budget". This is the starting point for drawing up the care plan, setting out the health outcomes to be achieved and how these goals might be met. The care plan should then be costed and a final budget agreed. Staff setting the budget will need a clear idea of local average costs for care agencies, brokerage and PAs. Where an individual wishes to employ their PAs directly, the budget will need to include recruitment, training and insurance costs.

How to quantify a DP

Under regulation 13, the health body must ensure that the amount of the DP paid to, or in respect of, a patient is sufficient to provide for the full cost of each of the services specified in the care plan. If the health body becomes aware that the patient's health status has changed significantly but believes that a review is not necessary, the health body must be satisfied that the amount of the DPs remains sufficient to provide for the full cost of each of the services specified. The health body may at any time increase or reduce the amount of the DPs, provided it remains sufficient.

The health body may reduce the amount paid by way of DPs where DPs have accumulated and remain unused if it considers it reasonable to offset the monies accumulated against the outstanding amount to be paid for that period. The reduction cannot exceed the outstanding amount. If a health body does decide to reduce the amount of the DPs, it must provide reasonable written notice to the patient/representative/nominee with reasons. The patient/representative/nominee may ask for this decision to be reconsidered. The health body is not obliged tor reconsider more than once.

If the health body has a policy (as many do) that caps the spend on domiciliary CHC packages, the health body will have to decide whether a DP in this context would breach the policy; it will usually trigger an application under an exceptionality provision that enables the CCG lawfully to make a DP that exceeds the financial cap set in the policy.

The care plan and care coordinator

The care plan must specify:

- The health needs to be met and the health outcomes intended to be achieved.
- The services to be secured by means of the DP that the health body considers necessary to meet the health needs of the patient.
- The amount to be paid and at what intervals payment is to be made.
- The name of the care co-ordinator for the patient.
- Who is to be responsible for monitoring each health condition of the patient in respect of which a DP may be made.
- The anticipated date of the first review and how it is intended to be carried out.

- The period of notice that is to apply if, following a review, a health body decides to reduce the amount of the DP or stop making the DP altogether.

In drawing up the care plan, the health body must be satisfied that the health needs identified in the care plan can be met by the services specified in the plan. Once the care plan has been costed, the health body must be satisfied that the amount of DP will be sufficient to provide for the full cost of each of the services specified.

Before making a DP, the health body must advise the patient/representative/nominee of significant potential risks arising out of a DP arrangement, the potential consequences of those risks and any proportionate means of mitigating those risks. The health body must also agree with the patient/representative/nominee the procedure for managing any significant potential risk and include the agreed procedure in the care plan.

These might include the following risks, for example:

- To the patient's health.
- Medical/surgical risk arising from the procurement of a particular type of service.
- Arising from the employment relationship where the DP will be used to secure services from an employee (eg: a PA).
- Arising from a provider operating under an inadequate or no procedure for the investigation of complaints.
- Arising from a provider operating under inadequate or no insurance or indemnity cover.
- That monies paid by way of DP may go missing, be misused or be subject to fraud.

If the health body has considered including a particular service in the care plan but then decides not to include that service, the patient/representative/nominee may ask the health body to provide the reason(s) for the decision and the health body must comply with that request. The patient/representative/nominee may also require the health body to reconsider its decision and may provide evidence or relevant information for this purpose. The patient/representative/nominee must be advised of the decision on reconsideration and provided with the reasons for the decision. The health body cannot be required to undertake more than one reconsideration.

Before a DP can be made, the patient or their representative must agree that:

- The patient's specified health needs can be met by the services specified in the care plan.
- The amount of the DP is sufficient to provide for the full cost of each of the services specified in the care plan.
- The patient's requirements may be reviewed in accordance with regulation 14(2).

As part of the process, the health body must also nominate a care coordinator to be responsible for:

- Managing the assessment of the patient's health needs for the care plan.
- Ensuring the patient or their representative has agreed to the matters in the previous paragraph.

- Monitoring or arranging for the monitoring of:
  - The making of the DPs.
  - The patient's health conditions in respect of which the DPs are made.
- Arranging for review of DPs.
- Liaising between the patient/representative/nominee and the health body in relation to the DPs.

Restrictions on who may provide services where a DP is being made: family members and friends

A health body may specify in a care plan that a service may be secured for a patient from:

- An individual living in the same household as the patient.
- A family member (ie: the patient's spouse, civil partner, cohabitee, parent or parent-in-law, son or daughter [including step children], son-in-law or daughter-in-law, brother or sister, aunt or uncle, grandparent; or the spouse, civil partner or cohabitee of any of the aforementioned people).
- A friend involved in the provision of the patient's care.

Whether or not such a person is a nominee, **only** if the health body is satisfied that securing a service from that person is necessary to meet satisfactorily the patient's need for that service or to promote the welfare of a child patient.

Provision of information, advice and support

A health body must arrange for a patient/representative/nominee to whom DPs are made to obtain relevant information, advice or other support. This may relate to:

- The amount of a DP and how this is calculated
- How a review of the patient's DP and care plan can be requested
- The circumstances in which a patient may no longer qualify for a DP
- The restrictions on how a DP may be spent
- The process involved in drawing up and agreeing the care plan
- Provision for advocacy services
- Procuring services
- Provision for payroll, training, sickness cover or other employment-related services
- Integration (where relevant) with social care DP

If the care plan specifies a requirement for information, advice or other support, that support may be a service in respect of which DPs may be made.

What must the health body be satisfied about before it can make the DP into a bank etc account?

Unless the patient is in receipt of a one-off DP[2] (which may be paid into their ordinary personal bank account), the health body must be satisfied that the account is capable of providing for monies paid into it to be held **only** for the purposes of securing services by means of health DPs, social care DPs, ILF payments or other payments to secure relevant services for a disabled person. The account, which must only be accessible by named persons approved by the health body, must also be capable of being audited (by reference to statements) by the health body or anyone authorised by the health body. The DPs paid into the account can only be used for services agreed in the care plan.

What must the patient ascertain before securing services from a provider?

A patient/representative/nominee must be sure, before securing services from a provider, that the provider, if carrying on a regulated activity [within the meaning of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010] is CQC-registered, is registered as a member of a profession regulated by the GMC, GDC, GOC, GOstC, GChC, GPhC, NMC, HCPC etc., and – where necessary – the provider has adequate insurance or indemnity cover. The patient/representative/nominee is entitled to ask the health body to makes these enquiries.

The health body is entitled to insist that the patient/representative/nominee does not secure a service from a particular individual.

Updating the health body during the life of the DP agreement

The patient/representative/nominee should update the health body periodically about progress against outcomes and inform the health body if the circumstances or state of health of the patient changes substantially.

Any information which must be provided to a health body under the regulations must be legible, accompanied by the relevant authorisation enabling copies to be taken where appropriate, and (if the health body requests it) accompanied by an explanation.

Monitoring and review

The health body must monitor the making of DPs to or in respect of a patient and the health conditions of the patient in respect of which DPs are made.

The health body must review the making of DPs to or in respect of the patient at appropriate intervals and at least once within the first three months of the DPs being made and then at least annually. A review may be necessary when the patient's health status changes significantly.

If the health body becomes aware that DPs have not been sufficient to secure the services specified in the care plan, the health body must carry out a review.

When carrying out a review, a health body must:

- Review the care plan to establish whether it continues to provide appropriately for the patient's health needs.

[2] ie: A payment made for a single item or service or a single payment made for no more than five items or services where that payment is the only payment a patient would receive from that health body in any financial year.

- Consider whether the DPs have been used effectively.
- Consider whether the amount of the DPs is sufficient to provide for the full cost of each of the services in the care plan.
- Consider whether the patient/representative/nominee has complied with their obligations under the regulations.

The health body may also reassess the patient's health needs, consult with any of the aforementioned individuals, review financial information relating to the use of the DPs, and consider whether the DPs have been effectively managed and spent with appropriately registered and insured providers.

A patient/representative/nominee may ask the health body to carry out a review.

In light of the outcome of the review, the health body may take any action it considers appropriate, including amending the care plan, substituting the patient for the representative/nominee (or vice versa) as the person to whom the DPs are made, increasing/maintaining/reducing the amount of the DPs, insisting that a service is not secured from a particular person or requiring the patient/representative/nominee to provide necessary information.

Where the health body decides to reduce the amount of the DPs, or stop making them altogether, it must give reasonable written notice to the patient/representative/nominee. The health body can be asked to undertake a further review by the patient/representative/nominee but is not required to repeat this exercise more than once.

Repayment of Direct Payments

A health body may require part or all of a DP to be repaid, if satisfied that this is appropriate, having regard to the care plan or the patient's circumstances having changed substantially, a significant proportion of the DPs having accumulated, DPs having been used for a purpose other than for a service specified in the care plan, theft/fraud/another offence having been committed in connection with the DPs or the patient having died.

Where a health body decides that a repayment is required, it must write to the patient/representative/nominee on reasonable notice, stating the reasons for the decision, the amount to be repaid, the timescale for repayment and the person who must repay (this will be the patient's personal representatives, in the event of the patient's death). The patient/representative/nominee may ask for a reconsideration of this decision but the health body is not required to undertake this exercise more than once. The health body may waive any repayment requirement. Where a sum must be repaid because of theft/fraud/another office having been committed, that sum may be recovered summarily as a civil debt.

Stopping payment

A health body **must** stop making DPs when the requisite consent (ie: of patient or representative) is withdrawn. It **may** stop in any appropriate circumstances or if the person in respect of whom payment is made ceases to be a patient or dies, the DPs have been used other than for a service specified in the care plan, the heath body considers that the heath needs of the patient cannot be or are not being met by services secured by means of DPs, the health body considers that theft/fraud/another offence may have occurred, the nominee does not agree to receive payments, the nomination of the nominee has been withdrawn or the health body does not consider that the representative/nominee is a suitable person to receive direct payments in respect of the patient.

Where the health body decides to stop making payments, it must give reasonable notice in writing to the patient/representative/nominee, providing its reasons. The patient/representative/nominee may request that the

health body reconsiders its decision but the health body is not required to undertake this exercise more than once. The health body may stop the payments, in the interim, even where a reconsideration has been requested.

Any right or liability of the patient/representative/nominee in respect of or to a third party, acquired or incurred in respect of a service secured by means of a direct payment, shall transfer to a health body when the health body stops making DPs.

Conclusion

Although a Personal Health Budget sounds quite a fluffy, friendly concept, commissioners should be under no illusions: a Direct Payment agreement is a binding contract between the patient/representative/nominee and the health body and needs to set out in comprehensive form the respective obligations and rights of the parties. The detailed content of the regulations needs to be reflected in the agreement, to protect both the health body and the patient/representative/nominee, and to ensure that both parties are clear about their responsibilities.

The resulting agreement will look very formal but commissioners should not be tempted to substitute a couple of non-scary-looking pages so as not to risk patients finding the agreements off-putting. This would be false friendliness and would serve the interests of neither party. Contracts are there to protect the parties' interests and to provide clarity about what it is that the parties have agreed. Nowhere could this be more important than in the field of NHS Continuing Healthcare and Continuing Care for Children, where patients may have complex conditions and complicated lives.

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