



**NORTHUMBERLAND**

**LINK**

**Enter and View Report**

**Users of Direct Payments**

**29<sup>th</sup> March 2011**

**Blyth Community Enterprise Centre**

**Enter and View Authorised Representatives**

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# 1. Introduction

## a) Direct Payments

Direct Payments are payments made in lieu of social services. They offer people who are assessed as needing community care services the opportunity to arrange their own personalised care, rather than receiving services directly provided by a local authority. Direct payments have been available for adults of working age since 1997. The scheme was extended in 2000 to include older people and was further extended in 2001 to include carers, parents of disabled children and 16 and 17 year olds.

Anyone aged sixteen or over who is assessed by a care manager as needing community care services has a right to opt for direct payments, though there are a few restrictions:

- The person must be willing and able to manage the paperwork and responsibilities involved (with someone helping them if necessary)
- They may not be eligible if they have been detained under mental health legislation
- Carers can only get direct payments to replace services provided directly to them – they cannot get money to buy services for the person they care for.

Direct Payments can be used as follows:

- Direct payments can be used to pay for personal assistance – for instance the person can pay for help from an agency, or can employ someone (including live-in assistants). They can also be used to pay for daytime care or for short breaks or special equipment.
- They can **not** be used to pay for general living expenses (e.g. fuel bills), or for health or housing services. They cannot be used to pay for services provided by a public-sector organisation, and they cannot be used to pay for long-term residential care. They cannot normally be used to pay a partner or a relative who lives with the person.

## b) Continuing Health Care

In June 2007, the Department of Health published the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, following public consultation during 2006. The guidance in the Framework is part of the Department of Health's continuing care policy in England.

If a person's main need for care relates to their health, the NHS is responsible for providing for all of their needs. NHS Continuing Healthcare is a package of continuing care arranged and funded solely by the NHS. It's also sometimes known as fully funded NHS care.

To be eligible for NHS Continuing Healthcare, the person's main or primary need must relate to their health. Their needs will be assessed to decide if they are eligible.

If they are eligible, they are likely to have a complex medical condition that requires a lot of care and support; they are also likely to need highly specialised nursing support. NHS Continuing Healthcare may be provided in any setting, for example:

- in a person's own home. The NHS will fund all the care required to meet their assessed needs, or
- in a care home or nursing home - the NHS will make a contract with the home and pay the full fees for the person's accommodation, as well as all of their care.

### **c) Northumberland LINK**

Northumberland LINK has had a keen interest in the development of the Transformation programme which is establishing new arrangements for adult care and support in Northumberland. A Personalisation Task Group was set up in 2009 to consider issues arising from this, and engage with Northumberland Care Trust.

In January 2011, Jane Bowie from Northumberland Care Trust and Jackie Welsh from North of Tyne NHS Trust, were invited to a meeting of the Task Group to discuss Direct Payments and Continuing Health Care respectively. An issue was raised concerning the support that people receive who are receipt of Direct Payments or Continuing Health Care, and whether there are any gaps in the support.

## **2. Purpose of the Enter and View**

On 2<sup>nd</sup> March 2011, a meeting took place of the Enter and View Steering Group. Following on from the Personalisation Task Group, it was agreed that 2 of our Enter and View Authorised Representatives meet with a group of people who use direct payments or who are funded through Continuing Health Care, to ask for their views about the support that they receive. This meeting would take place under the remit of Enter and View, and a report would be prepared. The issues to be considered were:-

- The support received from the Direct Payments Team from the time that the person was informed by their care manager that they had been awarded a direct payment
- Understanding their role as an employer and the use of brokerage or payroll services
- Support networks for people in receipt of Direct Payments and Continuing Health Care.

### 3. Methodology

A meeting was arranged on 29<sup>th</sup> March 2011 at Blyth Community Enterprise Centre.

Members of the Direct Payments customer reference group were invited by Debra Dodds, Team Manager, Self Directed Support Team. Adapt NE operate a payroll system for users of Direct Payments, and invited people who use this.

The meeting was attended by two users of direct payments, two Enter and View Authorised Representatives, and steering group observers.

Debra Dodds, Direct Payments Team Leader, met all present and left to allow responses to be made openly, and then returned at the end of the meeting in case her input was needed and to see how the meeting had gone.

Two further telephone calls were made with people who were unable to attend the meeting, one of whom is funded wholly by continuing healthcare.

**[See appendix 1 for full list of participants]**

The information contained in this report was collected by semi structured interviews with service users and carers.

**[See appendix 2 for questionnaire used]**

### 4. Findings

#### **a) The four users of direct payments:**

- i) The first user of direct payments was AH, who is carer for her husband, who accompanied her to the meeting. They live on a remote farm. Her husband has developed schizophrenia, which has necessitated short and difficult residential periods at mental health homes in Newcastle. Her husband has 10 days of respite care annually.
- ii) The second user of direct payments was MH. He and his partner have six children. The eldest two, aged 19 and 17, have both been diagnosed with Juvenile Huntington's disease, a degenerative neurological condition which progresses in 'steps' and eventually demands that constant care of the person has to be taken. MH's partner is the children's registered carer but so far as they are aware, she has not had a carer's assessment, which could possibly mean they were eligible for more funding. They have 14 days respite care annually.
- iii) The third user was Mrs H who was interviewed by telephone on Monday, 11 April 2011. Her husband has Primary Progressive Multiple Sclerosis (PPMS). He now uses a wheelchair, and needs two helpers with him at all

times. Mrs H also has a separate direct payment of £20 a month to give her a break of 5/6 hours away from caring.

- iv) The fourth person was JH who was also interviewed by telephone. JH lives with her daughter who is in her early 20s, and is severely disabled. Originally, her daughter's care needs were met through social care and Continuing Healthcare, but now they are met through Continuing Healthcare only through NHS North of Tyne. JH is her daughter's main carer. The funding is paid by NHS North of Tyne to Adapt NE as a broker, who then pay JH for her role as her daughter's carer. JH works for 62 hours per week. She does not have a contract.

#### **b) Information and support provided by the Direct Payments team**

- i) AH applied for a Direct Payment 3 years ago. AH had been introduced to direct payments by the CPN (Community Psychiatric Nurse). She had a carer's assessment with a view to receiving direct payments for herself to alleviate her situation as full time carer. She was satisfied with the information and support she had been given by the Direct Payments team.
- ii) MH felt his experience of the direct payments system and meetings with his Care Manager had been the best he had had in years of battling with difficult encounters with professional people on behalf of his sons. He said he 'couldn't fault' his Care Manager. The whole process of receiving direct payments and being advised on how to manage them had gone well. The paperwork had been there promptly so that he could begin looking for support workers immediately.
- iii) Mrs H had used direct payments a few years ago for short breaks, but this system was stopped. By last April her husband's situation had progressed to the stage where she needed to hire carers, and she approached the Direct Payments team for help. Mr H has a Personal Budget to cope with his needs. Mrs H said that the team has been really helpful, in providing a booklet about direct payments, helping to find carers and suggesting ways of paying them and dealing with the paper work required. If Mrs H has any queries, she is happy to telephone the office and will always be provided with an answer there and then or telephoned back later. She has complete confidence in them. The couple have met Support Planners from County and Mr H has a Care Manager who has also been very helpful.
- iv) JH said that it had been agreed that her daughter's care would be fully funded through a Direct Payment in June 2010, but the arrangements were not set up for several months, and funding for her care needs was split between social care and continuing healthcare. JH then received a letter stating that funding would no longer be paid through social care. Following this, there was a review, and in November 2010, funding was paid through Continuing Healthcare only. This uncertainty caused a great deal of anxiety. JH said that once it had been agreed that her daughter's

care would come under Continuing Healthcare only, the arrangements should have been sorted out more quickly.

**c) Employing support workers; information and training given on being an employer; using a payroll service**

- i) AH has found herself a support worker locally who provides her with support in the house for four mornings a week. He does shopping, a little housework and things like taking the dogs to the vet's. He is not usually involved in caring for her husband, though he does occasionally stay over when AH is away. If her support worker is not available, then AH can employ another person who is also a carer for her own husband, to look after her husband.

She has found the employer role easier, as she uses the payroll service provided by Adapt NE. She was their first customer and is pleasantly surprised at how small the charge for the service is.

AH did not say whether she had received any information or training in her role as an employer.

- ii) MH has a choice of two or three support workers for his son from two different agencies. They take his son out on visits to whatever he wants to see or take part in.

He would consider employing a support worker himself, when the time was right, but at present he has been glad to use the agencies.

- iii) Mr and Mrs H were helped by the Direct Payment Team to find their three carers. The carers' pay and all paperwork relating to their work is dealt with by a private company who run a payroll service, Accountability. Mrs H says they were given a choice of suppliers but as this firm were known to the team to be effective, they went with them. Mrs H is sent the carers' wages slips to hand over to them, but after that she has no further work to do in that respect.

The £20 per month is provided to support Mrs H by paying for someone else to take Mr H out. This figure is meant to cover petrol and lunch for the carer and Mr H. She thinks she may be expected to fund part of the cost herself, but is not sure. Her daughters could take their father out to the cinema, for example, but they are not eligible for the £20 fee. She understands the reason for this.

- iv) JH is her daughter's main carer and works 62 hours per week. JH said that she is paid through Adapt NE in their role as a broker. JH does not have a contract from her employer, (her daughter), and feels that it would be easier if she had one, which she has requested.

Her daughter also uses an agency who provide personal assistants to support her. If JH were to reduce the hours that she cares for her

daughter, she believes that her daughter would like to employ someone herself to share the care with her mother, so that she has continuity with the same 2 carers who she knows well and who know her.

#### **d) Provider services and Support networks**

- i) AH has not used her direct payments to access other services or for activities, as her payments are solely to provide her with support in the home.

She has found her membership of Carers Northumberland of great assistance. There is a mental health support group and support for carers.

- ii) MH was given the booklet, 'Children and Young People with Additional Needs in Northumberland: a guide to local and national services', which is produced by Northumberland Parent Partnership Service. He has found this invaluable in sourcing activities and services for his sons. He has found the names, places, telephone numbers, information about who is responsible or where to get information – all accurate and reliable.

He is a member of the Huntingdon's Disease Association and has found their advice and support most useful over the past 16 years. He has met local and national representatives and found the Juvenile Huntingdon rep extremely helpful.

- iii) JH said that she does not know of any support networks for people funded through Continuing Healthcare, and that there are no independent organisations to provide advice and support, although she does contact Adapt as a broker. She believes that support networks do not exist at present as Continuing Healthcare is very new.

## **5. Conclusions**

### **a) The support received from the Direct Payments Team**

In relation to Direct Payments, each of the people interviewed said that they had been well supported by the Direct Payments team, and had received information at an early stage.

In relation to Continuing Healthcare, there was concern that there had been a long delay from when it had been agreed to fund the person solely through Continuing Healthcare, and the arrangements being set up. This led to stress and anxiety. More communication is needed so that issues can be resolved more quickly.

Direct payments are working well, in allowing people the freedom to choose for themselves whatever form of help seems most appropriate in their circumstances. However, they are bound by the rules and principles involved in applying direct payments. For example, the person spoken with by telephone was not allowed to

pay money to her daughter to take out her father; that money had to be paid to a personal assistant from outside the family.

Recipients are using imaginative and positive ways of using the funds to give a better quality of life to the people with needs to be met.

#### **b) Understanding their role as an employer and the use of brokerage or payroll services.**

In relation to Direct Payments, two of the people interviewed use a payroll service when employing support workers, and the third uses an Agency. None said that they had been given information or training about their role as an employer, or about the legal implications of being an employer.

In relation to Continuing Healthcare, the carer who was interviewed was concerned that she did not have a formal contract, and felt that it would be better if she did have a contract.

#### **c) Support networks**

Support networks and organisations referred to were Carer's Northumberland, Huntington's Disease Society and Age Concern, a combination of local and national organisations.

The booklet, 'Children and Young People with Additional Needs in Northumberland: a guide to local and national services', produced by Northumberland Parent Partnership Service, was found to be invaluable in sourcing activities and services.

There appear to be no support networks in Northumberland for people funded through Continuing Healthcare, nor independent organisations to provide advice and support.

## **5. Recommendations**

- Information about Direct Payments should continue to be provided at a very early stage of an application so that applicants are fully informed.
- More information should be provided about Continuing Healthcare, so that more people are aware of it, and can access it more easily should the need arise.
- Information and training should be provided for people who are to employ their own support workers about the legal implications of being an employer, and about how to deal with situations, and who to contact if difficulties arise. None of the people interviewed referred to any difficulties experienced as employers, but it is felt that people should be informed of difficulties that could arise, and systems should be in place to support them to resolve these.

- Information about both local and national organisations should be provided for people when they apply for Direct Payments or who are funded through Continuing Healthcare.
- As Continuing Healthcare is relatively new, independent support should be set up for people to access support and information, and share their experiences with others.
- A directory of service providers, services, organisations providing aids and adaptations, and sources of financial help for vulnerable adults and their carers should be produced. The directory of services available for children referred to by MH could be a model for this.
- It would be useful to have this exercise repeated again at an interval of time, to check that this new means of giving social support is continuing to be well received.