

Report from Independus Forum on Direct Payments

The Golden Lion, Northallerton,

5 April 2011

This was a very well-attended Forum with people from a wide range of backgrounds and localities across the county. It demonstrated the importance of, and interest in, this topic.

Mike O'Neill welcomed everyone and promised that we would try to stick to our timescales as it was a tight schedule. He introduced Emilia Cook, Service Development Manager (self directed support) who gave us a clear outline of the process of getting a Direct Payment, going from the initial assessment of need to the establishment of the payment and how it was monitored and reviewed. She was followed by Anne Davidson, a Direct Payments Support Worker who talked about the day to day management of the system and her role.

After coffee there were workshops which focused on the early assessment part of the process which our research had indicated was a key issue. As anticipated, the workshops raised many issues which are attached in full as an appendix.

Common themes were:

Information about direct Payments was very inconsistent, people learned about it from many different sources, peers, other organisations, internet etc. It would seem that a standard should be set at assessment time that people should have this information given to them in a clear and positive way by their care manager (or other assessor).

People did not at all understand the difference between Personal Budgets and Direct Payments (even after an explanation being given during the presentation).

People needed support during the assessment process which could be a very difficult time. This was not always given recognition, assumptions were made and people did not know how to challenge things. It was felt that there was a lack of clarity and the process could be very subjective depending on the perspective of one person.

The review process was flawed with some people being reviewed by telephone and told budgets were being cut without proper assessment of need.

Carers' needs were sometimes not taken into account.

Several people raised issues about the qualifications of the assessors to make judgements. They felt they were confused and negative. Assessment is the key to the whole process and there was little confidence that it was being carried out in a way which enabled disabled people to enjoy a good quality of life and fulfil their aspirations. They felt that having someone who was responsible for the budget as well as the assessment inevitably compromised the process. Therapeutic activities such as art or music were seen as

“luxuries” although for people with learning disabilities or mental health issues they might be key to their lives.

After the feed back session and an excellent lunch we enjoyed a presentation from two people who use Direct Payments and were able to tell us about the difference that this had made to their lives – moving from the constraints of residential care to their own homes, making choices about their lives in every way. Difficulties were recognised but despite the challenges both Shaun and Andy would never go back to the institutional model of life.

All in all, a really enjoyable and interesting day which raised many issues for us to take back and work on!

Appendix

Group one...feedback from questions 1 and 2 from Direct payments workshop. 5/4

Qn. 1 How did you learn about Direct payments? Were you given good advice about what they are and the difference between Direct payments and a Personal Budget ?

The members of the group were all professionals with knowledge of both NYCC and other areas.

Learnt about Direct payments in a variety of ways...

- a. Someone learnt about DP from another area
- b. Another due to a placement with Mental health services
- c. When they applied for a job in 2007 with Wilf Ward..heard about same in job interview.

Information from group then indicated that Hartlepool quite progressive with Direct Payments....

H'Pool tender services out so they signpost clients to these services ie payroll. HR services etc.

N.Yorks only advise clients re using credit union for advice.

Key discussions were around clarity being needed for direct payments and the assessment process.

Personal Budget v Direct payment

Points made....

Do people really know the difference ?

Do Social workers know !

General view was the process is confusing and not simple enough.

Qn 2. What support were you offered ? Any time to prepare for the assessment ? Were you able to speak with someone already receiving Direct payments ? Were you offered Advocacy or support ?

The group had no first hand knowledge of the process, but had second hand info through CAB, clients etc...

One example was an assessment being carried out in hospital...luckily daughter was present to provide some support.

General concerns

- a. client alone with assessor, who is probably a stranger....problem of embarrassment and admitting what they can't do.
- b. Difficulty about discussing personal life..invasive.
- c. Issue of questions themselves..some early ones relate to Health and Safety issues of the assessor !
- d. Whole assessment is very subjective by one person, and then can be interpreted by the supervisor ?
- e. Assessment takes a long time..what about breaks etc as appropriate depending on the client and possible Age/Disability.

No-one in the group had any evidence about guidance being given before the assessment.

Only feedback relates to adverse experiences via C.A.B. on assessment itself, information given and the financial outcome.

Concerns also that the **assessment is based on a medical model and not social model** .

Overall there were two **main concerns of the group**.

1. A lack of transparency about the system.
2. Why do NYCC not look at other areas for best practice.....no point in re-inventing the wheel.....some Local Authorities are much further ahead ..reap the benefits of their work !

Table two

Question one.

Through a social inclusion group – New Horizons supported by NYCC . Carers for each other and using a budget from A&CS contract. Were asked to move to Direct payments. Group of 7 were assessed as a group.

After 2008 each person was assessed individually, the assessments are done by different people from three different areas. Eligibility criteria was social inclusion.

This year 2 people were assessed by a visit to see if anything had changed, one by phone and the others got letters telling them what they were getting.

Through Independus . Not explained very well by social services. Doesn't get direct payments, said not applicable at the time. Recently assessed and spoken to an OT. 2006 Social services said she didn't qualify for ot. Ellie didn't want anyone one in her house at the time.

Aware by sharing notes other people using direct payments budgets were being cut this year without re-assessment or review.

Person was visited for 15minutes and their budget was cut though nothing had changed from previous year.

2 years ago Gillian made an enquiry to see if ellie could be eligible now but was told she wasn't

Question 3

How to challenge decisions without proper explanation. Are decisions documented and properly recorded as evidence/ Are interviews by assessors taking into account a person's ability to process information they are asked to provide/

Are people told they can have an advocate or other person with them to help them understand. Calibre of assessor, understanding the needs of the person before they visit.

How are NYCC taking into account the needs of the carer, do carers know about the two carer's assessment forms. Interview carer on their own to make sure their views are counted.

Carer for father in law(MS) 2002 Mother in law. Moved in to care for him as he didn't want to go into a care home. Moved house with a cottage so he could be supported with family having own life..

Became critically ill (9 wks in Hospital) care needs total24/7 care needed. A&CS asked for help. Visited & judged on size of house said had too much money and didn't help. Two children to support also and had breakdown. A&CS said she hadn't asked for help.

Put some care in but not enough to meet their needs. (2003) Offered Direct payments. Father in law not assessed just gave amount they would pay. Wasn't set up properly. Direct payments support helped set up account but carer still expected to do 24/7 as well as own job.

2008 – long stay\y in hospital deteriorated further. A&CS were in discharge meeting. No re-assessment since 2003. Said they would do continuing care package but waited till Jan 11 for this assessment.

£10 for all documents for subject appeal, given details of everyone else on direct payments & their payment history.

All given to local ombudsman for full investigation.

No Health assessment for last 6 years.

Notes on Direct Payments Workshop – Table 3

5 April 2011

1. How did you learn about Direct Payments?

Were you given good advice about what they are, how they can be used, and the difference between direct payments and a personal budget.

Information found on a website.

Advice from a disability organisation

Through other people who had Direct Payments

Through a friend – very vague information.

One person had been on the old Personal Assistance Scheme and was helped to move on to Direct Payments

One person had his social needs assessed and received a Direct Payment but did not feel he had had information about the system in general.

There was a general feeling that information was poor, people were confused about the different terms and the process. Staff also seem confused and negative which results in many disabled people feeling disengaged..

4. Were you asked to provide details of anyone who gives you help at any time? Were they also invited to attend your assessment so they could support you? Did the assessor ask them if they would like to be considered as support or if they were friends/family who do help on a voluntary basis and not as part of any care package?

One person had her mother to support her. This led to discussion of the issue about the individual having choice about who is there – sometimes the views of parent/partner may differ from the person. Assumptions are made.

It was also felt that the assessment of people who had no verbal communication was poor. They needed a knowledgeable member of support staff or family (if appropriate) to act as advocate who could interpret their feelings.

Doubts were expressed about the qualifications/abilities of the assessors. It was felt that disabled people should be able to participate in their training.

Disabled people should be supported by an independent organisation to present a portfolio of their needs. There was concern that assessors were linked to budgets which produced a conflict of interest.

The needs of disabled adults for things like art or music were seen as luxuries when they could play a very important part in their quality of life. Social needs faced the same barrier.

People with mental health issues needed peer support and this was not always understood.

Assessment was very confusing and the role of advocate was really important – whether peer/family or independent worker.

Assessors do not always communicate in an appropriate way taking the disabilities of an individual into account.

One person had a very poor review – 10 minutes – after which he was told his needs had not changed but his payment was halved.

After appeal and a proper assessment – 3 hours - (with an advocate) his payment was re-instated.

Table four

Question 1

How did you learn about Direct payments?

He learnt about dp through his mother & his 1:1 however doesn't know the difference between dp & personal budgets.

Having your personal budget in parts would make it easier, start with money for transport, then day support, carer support ect. Learn the skill of managing the money slowly.

Some knowledge through partnership board, has previously had dp and is aware of some of the principals surrounding dp.

As a student nurse taught about them at university.

Information given is slightly vague, unclear, confusing about difference between dp & budgets.

Diane came to Yatton House to give us a talk.

Carers need more information about indicative budgets. Lack of advice and information for families and carers.

No way of challenging assessors' decision.

Assessors should be independent of the council and should work in two's.

Should be told about where, when and how an assessment is carried out.

When a person is in hospital and the package of care is needed to enable them to go home the assessment should be done by the MDT not A&CS staff alone.

Training is a priority , well trained carers, ensure safety and prevent health inequalities.

Risk of social isolation

Question 5

I had two assessments (first was unsatisfactory) second with my advocate was better.

Independence in the assessor is needed

Good training for P.A'S is needed

I was made aware of how much but what I can spend it on is unclear.

It felt it was dictated how to spend & where to spend but I was told clearly how I couldn't spend it.

Table Five.

Question one.

How did you find out about direct payments/

Through a job, as a career, from another person receiving direct payments and from Independus.

Q2a where you given good advice ect?

Recieved good information from Independus , actual budget was indicative and not enough to cover identified need.

Information raises more questions than answers. Too much jargon – needs simplifying.

Has it been demonstrated that direct payments are better than direct services through NYCC.

Where is the independent monitoring and advice?

Are NYCC & A&CS really thinking of about the budget rather than realistic benefits of care? Need transparency.

2b Assessment findings and challenge.

Is he/she going to get better? Often inappropriate question!

There are differences in interpretation of care need and level of care given.

Care manager give no information on independent advice, information given is often not clear.

Care inadequate without support of parents/family/friends, often assumed but not legal requirement for the family to give care.

Need careers assessment when family have to give the care. Assessment needs to be person centred and often not.

Lack of communication between different providers & professionals, referrals often not carried through.

Re-assessment at 6 wks, often not given full information.

Budget restraints, need what can be offered not what you can do.

Personal budgets/direct payments do not appear to support people who would like to work or get training, holistic view of needs.

Need for assessment before people are discharged from hospital or schools/collages.