

Disability Equality North West – Learning Event

# *PERSONALISATION AND CUTS: How to fight for the support you need*

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## PERSONALISATION: What is it?

- **Self-directed support:** General term, referring to a variety of tools to give older and disabled people greater levels of control over how their support needs are met
- **Personal budget:** The definition by the charity In Control says that the **user** must:
  - know how much money they have in the budget, whether they receive it as cash (a direct payment) or not
  - be able to spend the money in ways and at times that makes sense to them
  - know what outcomes must be achieved with the money.

## Types of personal budget

- **Personal budget:** Money from Social Services
- **Personal health budget:** Money from Health (normally PCT)
- **Individual budget:** Money from one or more sources, which may include:-
  - Social Services
  - Independent Living Fund
  - Supporting People
  - Local Education Authority (e.g. for post-16 education)
  - possibly Health
  - funds for equipment, transport, employment and more

## 3 ways of holding and managing a personal budget or personal health budget:

- **Direct payments:** Cash paid to the individual or carers of a child to manage themselves, with or without support
- **‘Notional budget’:** Held by the council or PCT, but the individual (or carers of a child) know how much money is in the budget and discuss with a care manager or other nominated person about how to spend it
- **‘Indirect payments’:** real budget held by a third party: e.g. a user-controlled trust, voluntary or private sector organisation with CQC registration, who manage it on the individual’s behalf with input from them

## Outline of personalisation in social care:

- Individual completes a **‘self-assessment questionnaire’**
- The assessment is scored based on the level of need identified in the questionnaire, and converted into an **indicative budget** using a **Resource Allocation System (RAS)**
- A **support plan** is designed, with involvement from the individual, based on the indicative budget
- The support plan must be agreed – Funding Panel
- The arrangements are implemented and are subject to regular review

## Personalisation: New policy but not new law:

- NO CHANGE to the fundamental law governing assessment and entitlement to community care support
- **Person-centred** assessments/care plans have been around for decades; legally required at least since 2004
- **Direct payments** for social care legal since 1997 - can already do what is intended for personal budgets
- **‘Indirect payments’** by a local authority or PCT to a third party has been legal for much longer, used to make support packages more self-directed/personalised

## PERSONALISATION AND CUTS: Experiences so far

- The amount isn't enough to buy what you had previously
- Your social worker can't explain how the allocation of money relates to meeting needs
- No option of staying with directly provided services – this is presented as the new way of doing things
- Day and respite services are being closed but there is nothing else suitable that you can obtain locally
- You or your family are expected to do all the planning and arranging that was previously done by social workers
- Your family are expected to provide support for free, based on tickboxes on the Self-Assessment Questionnaire that you may not know the significance of

## Personalisation and cuts: experiences so far

- The hourly rate isn't enough to get properly skilled staff who will stay in post, especially where needs are complex e.g. challenging behaviour
- Restrictions on what you can or can't spend direct payments on; money clawed back if you don't spend it in a certain 'window'
- Large private sector providers taking over the management of direct payments packages so you don't feel you really have control – no choice about who helps you with payroll, recruitment and everything else
- No sense that you can challenge it or that you are **entitled to have your needs met, not just to get an 'allocation'**.

# Ten steps to getting and keeping the support you need...

# 1. Get an assessment of needs

- Assessment duty arises ‘where it appears’ that the person ‘may be in need of such services’ (s.47(1) NHSCCA 1990)
- Very low threshold to trigger assessment: not a question of whether the LA is likely to provide services; not dependent on a request by the individual; their resources/finances are irrelevant
- Carer who regularly provides substantial care has the right to an assessment of their own needs as a carer on request
- Right to a face-to-face assessment by a social services professional – a self-assessment questionnaire alone is not enough
- Duty to inform a relevant PCT, health authority or local housing authority to invite them to assist in the assessment if there is need for services provided by those bodies (s.47(3))

# 1. Get an assessment of needs (cont'd)

- Timescales:
  - None prescribed to complete an adult assessment, but the Local Govt Ombudsman (LGO) considered that 3 months for an adaptation assessment was 'simply unacceptable'
  - Disabled children: initial assessment within 7 working days and core assessment within 35 working days
  - Older people: Single Assessment Process to commence within 48 hours of initial contact and conclude within a month
- If the needs are urgent, a LA has a legal power to provide services on a temporary basis until the completion of the assessment
- If there are urgent needs and Health and Social Services are arguing about who is responsible for meeting them, then one must be nominated to provide in the meantime until the issues are resolved

# 1. Get an assessment of needs (cont'd)

Assessment must include the following (Community Care Assessment Directions 2004):

- consult with the person being assessed
- consult with a carer if appropriate
- take reasonable steps to reach agreement with the person (and carer) in terms of services to be provided to meet needs
- provide info about the amount of charge that the person may be required to make in respect of any services that may be provided

# 1. Get an assessment of needs (cont'd)

## Action:

- Ask for a face-to-face ***care assessment*** carried out by a professional from social services
- If you are only offered a self assessment form ask for a face to face assessment
- Get a carer's assessment for people who provide a substantial amount of care
- Have whoever you want to support you at the assessment

## 2. Identifying assessed and eligible needs

- The assessment should identify all needs: these are the **assessed needs** but not all will necessarily lead to support being provided
- To determine **eligible needs** the local authority must evaluate the **risks to independence** that would arise from each identified need **if it was not met** – i.e. assume no support from family or otherwise
- Evaluate the risks to 4 particular aspects of independence/well-being that are set out in the **eligibility criteria** of all local authorities:
  - autonomy and freedom to make choices
  - health and safety including freedom from harm, abuse and neglect
  - the ability to manage personal and other daily routines
  - involvement in family and wider community life

## 2. Identifying assessed and eligible needs (cont'd)

- All 4 aspects of independent living/well-being are equally important: e.g. needs about managing daily routines such as shopping and cleaning, or needs about being involved in family life or work cannot be treated as less important than needs about personal care
- For each need whether the risk is **critical, substantial, moderate** or **low**
- Each LA decides which of these bands is its threshold for eligibility for support. They must meet all needs above that threshold.
- The LA can meet needs below the threshold and is encouraged to do so to prevent needs escalating. In practice they will usually only do so by referring people to free charitable services.

## 2. Identifying assessed and eligible needs (cont'd)

- Carers' needs should also be identified by considering:
  - the sustainability of the caring role
  - how their caring role impacts on any work, education, training or leisure activity that they do or might wish to do.
- Carers can get support in their own right, which can be in the form of direct payments
- Eligibility for support for the carer is assessed using a similar risk analysis - i.e. whether there is a critical, substantial, moderate or low risk to the sustainability of the caring role
- Risks are in the same 4 areas of independence/well-being, eg how their health is affected, loss of autonomy because the caring role takes over, inability to look after their own domestic needs

## 2. Identifying assessed and eligible needs (cont'd)

### Action:

- Ensure all needs (and the level) are clearly identified in the assessment - otherwise they will not be funded
- Make sure carers' needs are identified and met as well
- Ask for a copy of your local authority's Fair Access to Care Services eligibility criteria
- If your support or services change, check that a re-assessment of needs has been completed- family carers should be consulted over this.
- If a re-assessment has not been completed, challenge any cuts as it is unlawful to reduce support or services without this

## 3. Get a care plan

- The written record of the assessment must include:
  - a note of the eligible needs identified during assessment
  - agreed outcomes and how support will be organised to meet them
  - a risk assessment including any actions to be taken to manage identified risks
  - contingency plans to manage emergency changes
  - any financial contributions the individual is assessed to pay
  - support which carers and others are willing and able to provide
  - support to be provided to meet needs identified through the carer's assessment, where appropriate, and
  - a review date.

## 3. Get a Care Plan (cont'd)

### Action:

- Check your care plan to make sure all your assessed needs are being met
- It must address all the 'how, who, what and when' and be clear
- Having a personal budget makes no difference - the care plan must still cover everything

## 4. Personal budgets / Direct payments

**Direct payments from a local authority may be paid to:-**

- an adult (over 16) with needs arising from age, disability or other factors
- the parents/carers of a disabled child, to meet the child's needs
- a carer (over 16), to meet their own needs as a carer
- a 'suitable person', to manage on behalf of an individual who lacks mental capacity to manage DPs themselves; the 'suitable person' may be:-
  - the individual's financial or welfare deputy or attorney
  - a family member or other close person.

## 4. Personal budgets / Direct payments (cont'd)

### Direct payments: How much should it be?

- ‘In estimating the reasonable cost of securing the support required, councils should include associated costs that are necessarily incurred in securing provision, without which the service could not lawfully be provided’, e.g.
  - recruitment costs, payroll services, CRB checks on employees
  - NI, VAT, stat holiday pay, sick pay, maternity pay
  - employers’ liability insurance, public liability insurance
  - start-up costs, training
  - brokerage/advocacy?
- Hourly rate
- Right to decline DPs, or use a mixture of DPs and direct services

## 4. Personal budgets / Direct payments (cont'd)

### Action:

- If the council suggest changing the support to a personal budget arrangement ask for clear information on what is involved and what support you can get to help manage the personal budget
- The council has the same responsibility to meet your assessed needs. If a personal budget results in a cut to your support when needs have not changed or been re-assessed, make a formal complaint (see point 8).
- You have the right to say no to direct payments if you would rather services were managed for you

## 5. Range and amount of support available

- Local authorities can't have 'blanket policies' such as:
  - 'We don't provide help with bathing without a doctor's note'
  - 'We don't provide help with shopping and cleaning'
  - 'We don't provide travel help anymore'
  - 'We don't provide evening/weekend services'
- They can't impose an upper limit on help, e.g.
  - 'If you need 24-hour care then it will have to be funded by Health'
  - The weekly personal budget can't be more than the cost of a care home

## 5. Range and amount of support available (cont'd)

### Action:

- If you are denied access to a particular type of support or a cap is placed on the amount of support you can get, check that:
  - 1) Your needs are clearly described in your care assessment
  - 2) Your care plan states how your needs will be met.
- Challenge any blanket bans or upper limits on the amount of financial support that is provided.

***The council has a legal duty to meet your assessed needs!***

## 6. Allocation or funding panels

The panel should not simply refuse to approve proposals put forward by the social worker who has done a detailed assessment of your needs, because of the cost

### Action:

- Request a written response from the panel which details how the council will fulfil its duty to meet the assessed need.
- If the panel's decision is unfair, complain (see below)

## 7. Lack of appropriate services and support

- Local authorities must adjust provision to meet your needs – not the other way round.
- Disabled people are entitled to choose where they live
- Local authorities cannot say:
  - ‘We don’t have anything suitable, so you will either have to use a service outside our area or you will have to arrange this yourself using a personal budget’
  - ‘We have funded you in an out of area care home and you are settled and happy there but now you must come back’
  - ‘Although there is an ideal service for you (such as a respite care home) we are not going to fund it because it is out of area’

## 7. Lack of appropriate services and support (cont'd)

### Action:

- If nothing suitable is available locally for you, ask for evidence that your council is taking steps to arrange or commission a new service, such as from a charity or other independent provider
- Ask how they will adjust provision to meet your needs.
- If your relative lacks capacity to decide where they live ask for a 'best interests' meeting. Family carers must be included in this meeting and the planning for what is best.

## 8. Making a complaint

### Action:

- If you believe that the Council has acted unlawfully, you should make a formal complaint to try to sort things out
- Get advice and help with your complaint from people who can support you – see points 9 and 10 below
- Ask for a copy of the Council complaints procedure and make sure you follow it
- A template letter to help you structure your complaint is available  
from: [www.lukeclements.co.uk/resources/index.html](http://www.lukeclements.co.uk/resources/index.html) (click on 'precedent complaint letter')

## 9. Identify some key allies

### Action:

- Get advice and help from people and organisations close to you like:
  - Your social worker
  - Your service provider
  - A local disabled people’s organisation (DPO) or other charity
  - An advocate
  - Your local councillor or MP
  - An independent support planner or ‘broker’

## 9. Identify some key allies

### Action:

- Different people can help with different things, such as:
  - Explaining clearly what is happening about your support and giving you the details in writing
  - Writing a letter of support for you
  - Helping you make a complaint
  - Putting you in touch with other people who have faced similar issues
  - Putting you in touch with other specialist help such as solicitors
  - Helping you set up your care arrangements, e.g. using a personal budget

## 10 . Get more information and individual advice

### Organisations:

- **Community Legal Service:** Website to find a solicitor, categories include community care, education and public law:  
[www.legaladviserfinder.justice.gov.uk/AdviserSearch.do](http://www.legaladviserfinder.justice.gov.uk/AdviserSearch.do)
- **Disability Law Service:** Provides telephone or email advice on community care law. Free to disabled people and their family carers.  
[www.dls.org.uk](http://www.dls.org.uk) Tel: 020 77919800 e-mail: [advice@dls.org.uk](mailto:advice@dls.org.uk)
- **National Autistic Society:** The National Autistic Society Community Care Service offers advice and information about Community Care  
[www.autism.org.uk](http://www.autism.org.uk) Tel: 0808 8004104 Email [communitycare@nas.org.uk](mailto:communitycare@nas.org.uk)

## 10 . Get more information and individual advice

### Resources

- **Carers and their Rights**, (2010). Professor Luke Clements. It is available on the internet free of charge at [www.lukeclements.co.uk/publications/index.html](http://www.lukeclements.co.uk/publications/index.html)
- **Using the Law to Fight Cuts to Disabled People's Services**, (2011). Doughty Street Chambers and Kate Whittaker, Irwin Mitchell Solicitors. Available on the internet free of charge [www.ncb.org.uk/edcm](http://www.ncb.org.uk/edcm)
- **Get your rights: What to do if your service is cut?** (2011). MENCAP. Available on the internet free of charge [www.mencap.org.uk](http://www.mencap.org.uk) Tel: 0808 808 1111

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