



all about people

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Factsheet: Family carers and personalisation

Why is personalisation important for family carers?

Personalisation is the word that is commonly used to describe a different way of delivering social care. It means that the whole system becomes person centred; this includes local government, organisations providing care and support, professionals and communities.

Personalisation will therefore mean big changes in many areas and it will take many years to get right. This change is often referred to as the 'transformation of social care'.

These changes are important because many people say that the current system doesn't work in a way that is easy for them to have choice and control. We also know that the current system will not be affordable as more people live longer and young people with profound disabilities survive into adulthood.

People rightly expect to have support that is tailored to their needs, to be able to have choice and control over things such

as who they live with, who supports them, how and when they receive support and what they do during the day. Family carers need to be supported in their caring role and to lead a fulfilling life themselves. They also want more say over how this happens, so they get the support that is right for them.

What does personalisation mean for family carers?

Personalisation refers to a system which enables everybody who needs support to lead a healthy and fulfilling life to have information, support and assistance at a time and in a way that is right for them. Family carers play an important role in Personalisation they know their family member better than anyone else, they are the experts by experience. Working together with local authorities and support providers to ensure the person they care for gets the support that is right for them.

There are some key principles that this new system has at its heart:

- Transparency and openness - people know how the rules and systems work and

what their entitlement to funding is - there is less mystery as to how decisions are made

- Fairness - the money is allocated in a way that is fair and equitable; this means that people in similar circumstances with similar needs should get a similar amount of money
- Partnership - it involves individuals and their families, local authorities and support providers working together
- The importance of communities - it is based on supporting people to remain a part of their community, and have a network of support in the community, not 'placing' people in institutions
- Valuing friends and families - 'informal' support that people get from friends and families is encouraged and supported in a way that is right for everyone
- Valuing people's knowledge and experience - people themselves and their families are respected as being the 'experts' in their own lives, able to draw on professional help as needed
- Including everyone - everyone can be in control of their lives and make choices about their support, regardless of their disability or whether they have families and friends to support them

In Control describe self-directed support as being when:

- You are in control of the money you get for your support
- You can choose how to spend the money for your support
- You can choose things about your life - for example, who you want to get support from
- You can get help to do these things if you need it

Self-Directed Support is therefore very like person centred support. But it goes further; the key difference is that the person knows how much money they are entitled to for their support and they have choice and control over how it is spent. This money is called a Personal Budget or (if it includes more than one type of funding), an Individual Budget.

The person is invited to complete a Self Assessment with as much support as they need. Family carers can be an important part of this. This simple process identifies what support the person needs to achieve key outcomes. It also asks them about what help they get currently from friends and family. Once they are given an indication of how much money may be available to them, they are able to plan how best to use it to achieve the outcomes identified in the Self Assessment Questionnaire.

One way that people have been able to buy their own support for many years is by having a Direct Payment. With a Direct Payment the person receives the money to buy their own support, through employing Personal Assistants for example. However, many people with learning disabilities and their family carers do not want to manage the money or be employers and that is OK.

Self-Directed Support gives people more choices; if someone does not want to receive the money they do not have to. But it doesn't mean that they can't still have choice and control over how the money is used. It is still their Personal Budget and they can say how they want it used, this may include using Council services or services from other organisations.

People can exercise as much choice and control over their support as they want; not everyone will want to make these choices

and many people will be happy with having services arranged for them. The important thing is that they are given the opportunity to exercise control *if they want to* and to have support to do so.

The other key difference with Self-Directed Support is that there are no rules about what the money can or can't be spent on (as long as it is within the law). The only thing that must be shown is how the activity or item they plan to spend the money on will meet the person's needs and help them achieve outcomes, such as a giving a break for carers or supporting more independence, etc.) This leads to much more creativity in how people spend the money and, as such, it can make the money go further.

How does it work?

In Control describes 7 steps to having self directed support:

1. The money - finding out how much.

The first thing to do is to find out if the person you care for can get money for support - and how much.

2. Making the support plan. The second thing is to make a plan with the person you care for about how the money will be used to get the life they want. The plan can be done by the person you care for. You can help the person you care for to do it. Organisations, friends or a care manager can help too.

3. Getting the plan agreed. A care manager at the council has to say the support plan is OK.

4. Organising the money. The money can be paid to the person you care for, to

you the carer or to someone who can look after it (a person, a Trust, a provider organisation or the care manager).

5. Organising my support. You can as a carer help the person you care for organise the support in a way that suits them. You can get help to find and organise support.

6. Living life. Services can be used you can also spend your money on local people who you know - or even buy things that will help the person you care for in their life.

7. Seeing how it worked. You have to show that you have used the money properly for the person you care for by showing that they have achieved what has been put into their support plan

Family carers experience of personalisation

A good way of showing how Self Directed Support works is to look at some real life examples of how family carers feel when the person they care for has a budget.

Mrs S

"I had some worries at the beginning of the process but IT IS working at last. It's what we want; it is helping with my son's confidence and anxiety issues. Brilliant to see my son enjoying himself again after all the problems we had. He is going to his sister's for his respite now giving me the break I need. The places he goes to are lovely and he is almost back to his old self. We are really pleased with how this is working for us".

Mrs AW

"This is just great for my daughter, she is happy with all that she is doing, going out meeting new people with support, the

learning to cook has gone a little out of the window because of all the different things she is doing, she now has a voluntary job working with older people, they have welcomed my daughter with open arms including her in all of their social events including the Christmas celebrations coming up. She has a lot more friends, which is good for her as she loves talking to people. I have a few worries but she is safe with her support staff, so we are happy.

I sometimes get a little worried over the money side of her Individual Budget but I know that I can make contact with social services and they can answer any questions we have.”

Mr and Mrs T

“It’s all working now, originally our son had respite nights as part of his support plan but he decided that he did not want to go on such a regular basis. After discussing it with our son’s social worker and with our son’s agreement, his budget pays for him to attend a work based employment preparation and training establishment near to where we live.

Our son’s self esteem is going up all the time since doing this, he has gained communication skills. Knowing that this is working for our son has given us greater peace of mind, he is learning something every day to help him get into employment in the future and that is good. He is in better health and his communication skills have improved. It’s all working for us. We go out to work each day knowing that our son is safe and happy in what he is doing.”

What do the words mean?

Personalisation

The process of moving towards a person-centred system for providing social care.

Self directed support

When people exercise choice and control in how they get the support they need.

Individual Budget

An amount of money from more than one source (not just the local authority) that is made available to meet a person’s support needs.

Personal Budget

An amount of money from the local authority that is made available to meet a person’s support needs.

Self Assessment Questionnaire (SAQ)

A questionnaire that people are asked to fill in that is used by the local authority to work out how much money the person is entitled to and what outcomes it needs to achieve.

Support Plan

A plan that is written to show how the budget will be used to meet the person’s needs and to support them to live their life as they wish.

Care Manager

The professional who carries out the assessment and writes the care plan on behalf of the local authority. Care Managers may be nurses or social workers by profession.

Social Services

The part of the local authority that is responsible for social care. These used to be called Social Services Departments but are

now commonly called 'Community' or 'Adult Social Care' services.

Provider organisations

Organisations that employ staff to support people. The organisations may be charities or private companies.

Other words you might come across;

Resource Allocation System (RAS)

A system used by the local authority to work out how much money each person is entitled to so that it is fair and affordable.

Person centred plan

A plan that is done with the person and those closest to them to work out what it is that 'makes them tick', what their hopes and dreams are and what 'a good life' means to them. A person centred plan is an ideal starting point for a support plan.

'Adult' or 'Community' Care Assessment

The assessment that is carried out by the local authority that takes account of the person's circumstances and what they need to be safe and well. It is used to determine whether the person is eligible for social care funding from the local authority and it records what specific needs the funding is for, along with any risks to the person that need to be considered. It is a statutory assessment which means that the local authority must carry out the assessment by law.

Care Plan

Following an 'Adult' or 'Community' Care Assessment a care plan must be written that sets out how the local authority intends to meet any needs assessed as eligible for funding and how any risks will be managed. It doesn't need to be too detailed but it gives an overview of the arrangements that will be put in place.

Individual Service Fund (ISF)

A 3-way arrangement between a local authority, the person (or their representative) and a provider organisation whereby some or all of the budget is paid directly to the provider organisation on the person's behalf, as identified in their Support Plan.

Broker

A paid worker whose role is to support the person and their family to work out how best to use the budget so that they get best value out of it. Usually they help develop the support plan and put services or arrangements in place. Brokers can be based in the local authority or they can be independent. They may be paid for directly by the local authority or the person may have to pay for their broker out of their budget.

In-house services

Services which are provided directly by the local authority and staff are employed by the local authority. In-house services need to be costed by the local authority so that people can choose whether to spend any of the budget on these services.

Trust

An arrangement whereby a group people (usually 3) agree to be 'Trustees' to manage another person's money on their behalf and in their best interests if the person is unable to do so. A Trust is a formal arrangement and there are legal duties and responsibilities of the Trustees.

References

In Control's first phase report
In Control's second phase report
Putting People First
Valuing People
Valuing People Now

Where to go for further information, advice and on-line discussions

www.bild.org.uk

Information, stories and resources relating to support for people with a learning disability

www.in-control.org.uk

Information, including the booklet 'What is Self Directed Support', available online and more information on the 7 Steps to being in control

www.supportplanning.org.uk

Lots of useful information about good support planning

www.helensandersonassociates.co.uk

Information about person centred thinking and planning in the reading room

www.carersuk.org.uk

www.familycarers.org.uk

Website of the National Family Carer Network. You can contact them by email: familysupport@hft.org.uk

www.dhcarenetworks.org.uk/

Information from the Department of Health

Thanks

This booklet includes adaptation of materials produced by In Control.

www.in-control.org.uk