

At a glance 10

Personalisation briefing



July 2009

Implications for carers

Key messages

Personalisation for carers means:

- tailoring support to people's individual needs and being part of the discussion about support for yourself and support for the person you are looking after
- not having to take on all the responsibility and all the managing of care and support – the local authority should ensure that you are sufficiently supported
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities – you should have your own needs assessed and have choices about your own support
- ensuring that people have access to information and advice to make good decisions about their care and support
- ensuring all citizens have access to universal community services and resources such as health, transport and leisure
- making services more flexible so you can agree outcomes and find solutions that are right for your situation
- if needs change over time, personalisation should enable you and the person you are looking after to change the way you are supported.

This At a glance briefing examines the implications of the personalisation agenda for carers.

Personalisation means thinking about care and support services in an entirely different way. It means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about what, who, how and when they are supported to live their lives. It requires a significant transformation of adult social care so that all systems, processes, staff and services are geared up to put people first.

The traditional service-led approach has often meant that people have not received the right help at the right time and have been unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives and goes well beyond simply giving personal budgets to people eligible for council funding. Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that people have wider choice in how their needs are met and are able to access universal services such as transport, leisure and education, housing, health and opportunities for employment regardless of age or disability.

What are the implications for carers?

There are two main elements to personalisation for carers. Firstly, personalisation should impact on the support provided to the person you are looking after, which may help both them and you. Secondly, personalisation should affect the support provided for you as a carer, after a carer's assessment.



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Example: Olu

'After my carer's assessment it was agreed that I could have a morning off each week and my mother could have someone to come in and sit with her. I employ a neighbour who knows my mum well with the direct payment I receive. Mum doesn't really like day centres. Before, I felt that as day centres seemed to be the only option I would just have to be with her all the time. But it was wearing me out. Direct payments allow me to get some 'me' time and I am sure that my mother also feels the benefits – she relaxes more and is not on the receiving end of my tiredness. The flexibility means that we can also pay someone to support us going out shopping if she wants to. It's the best thing we ever did. We are in control and can control how social services gets involved. We have tended to shy away from support in the past and do it alone, fearing intrusion.'

Personalisation in relation to the support provided to the person you are looking after

Everyone is entitled to an assessment of their needs. Following such an assessment, the person you are looking after will access support either through their local authority social care staff or by paying for support themselves independently of their local authority.

If the person you are looking after is arranging care for themselves independently of their local authority or you are undertaking this on their behalf, then getting advice about the support available and its cost might be important. Social services staff at the local authority of the person you are looking after should be able to provide information that will help you to arrange and pay for care independently. However, the availability, range and quality of this advice from local authorities may be variable. Help is also available from the Care Quality Commission (the regulator of care services), Counsel and Care or Elderly Accommodation Counsel for more information.

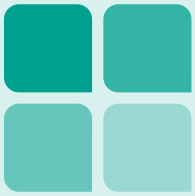
Their contact details are provided at the end of this briefing.

If the person you are looking after is accessing support through an assessment from their local authority social services teams, then both of you should carefully consider the following points to make sure that personalisation really works for both you and the person you are looking after.

Personalisation is not just about what social services can provide, it is also about what and how other public services can help – for example, through providing health, housing, transport, leisure services. What personalisation is supposed to do is find the solution that is right for you and meets your and your family's needs.

Making sure personalisation is working for your situation

- **Decide what outcomes you both want.** What do you and your family need? Do you have different needs within the family that have to be met? What other outcomes do you want as a carer? To work? To be able to visit family? Does the person you care for need to socialise a bit more? Are they really keen to get involved in the local community, but need support to do so? Or do you need basic help getting the person out of bed, dressed and washed?



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Example: deciding on outcomes

If you want to make sure that your father is safe, you will need to find out what support there might be that you could call upon. Would a day centre work for both of you? If your father does not want to attend a day centre then would an alarm system help to provide a safer environment and reassure you as his carer? Or do you think that a direct payment should be made that would enable you to employ someone to sit with him while you are out of the house? What solution will make life better for you both? Personalisation should be flexible enough to allow you to find a solution.

- **In some cases, it will be important to think how the care needs of the person you are looking after and your own needs might change over time and how this will affect what services you both need.** It may be that a day care centre works well now for the person you are looking after but in the future your home may need to be adapted and direct payments used to employ care workers to help out at home. Personalisation should enable you and the person you are looking after to change the way you are both supported over time. These changes might be important so that the caring does not get too stressful, your health does not suffer or you can continue working.
- **Are you being involved in the discussions about personalisation and the package of care for the person you are looking after?** Are you able to say how those plans will impact on you as a carer? This is important whether you are funding the care yourself or if social services are looking at funding the care. If changes are being made to a care plan, do the plans make life easier for you or more difficult?

- **If the person you are looking after is unable to manage making decisions about buying in care, etc, are you able to manage this?** If the care is being funded through the local authority, the local authority should be ensuring that you are sufficiently supported in this role and carers have told us that good advice is vital. Personalisation does not necessarily mean that you take on all the responsibility and all the work of managing care.
- **If you are taking on managing budgets, are they being properly resourced so that you can do this?** If you are employing staff, the budget needs to cover not just the normal staff costs, but also insurance, maternity leave, sick leave, emergency cover, recruitment costs, etc.

Example: carer involvement

If the person you are looking after is moving from three full days of day centre care to a four hours tailored support in the morning, this might mean that you have to provide care in the afternoon that was not previously necessary. This, in turn, may cause you difficulties. It might mean having to give up work – or putting extra pressure on your health and well being which may not be acceptable. If the local authority is funding the care you may have to argue that services or funding shall be made available to ensure that you are able to continue working and your health is better supported.



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Personalisation in relation to the support provided for you as a carer

The second element of personalisation is where you, as a carer, can have your own needs met by the local authority. This can be arranged through you requesting a carer's assessment from the local authority of the person you are looking after. If you are providing substantial care and doing this regularly then local authorities have a duty to take your needs into account when looking at what services to provide.

If you need to work, for example, then they have to consider this, or if you wish to study, or have time off from caring to pursue a hobby. They could either increase or change the services package of the person being cared for, or they could give you your own services.

Again, if your health is deteriorating and this is making caring difficult, or the caring is causing your ill-health, local authorities should be working with the NHS provide support, designed around your and your family's needs.

Once the local authority has decided how much support they can provide following your carer's assessment then you will need to make decisions about the way you would like to receive the support. You could leave it up to the local authority to make the arrangements for you, or you could take the money as a direct payment and buy in the support you need.

Example: June

'My mother isn't always comfortable with strangers providing the personal part of her care. Direct payments through the personalisation agenda allow me to buy help around the house, which I couldn't previously access under our old care package. This allows me to care without the pressure of having to do all the cooking and

cleaning as well. Often these domestic jobs just didn't get done, or I could only do them in a slapdash way. I work full time, but I can now also pay someone to look in on my mother to check she is OK whilst I'm at work. The key is flexibility – my mother's needs change and the services we buy with direct payments can change with them and fit around us.'



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Example: Rahilah

'Being a carer can change your relationship with the person you care for. I was worried and tired and stressed about many things – Mum had had one fall and I was worried it was going to happen again. There are lots of things she cannot do on her own and getting her out of bed, washing, bathing and then doing everything else had pushed me to breaking point. What was important to me was Mum keeping as well as possible and being able to do things herself for as long as possible – even if they are tiny things. It is really important to her and to me.

We went to our local authority and basically talked about what was important to each of us

and then they looked at what solutions would work for us. After the assessment which looked at all her needs, we got some great gadgets and the house was adapted which is much better for her and for me. I worry a lot less about her hurting herself by falling over and it has made caring much easier physically. Direct payments have allowed us to get back some of that mother/daughter relationship. I would not change providing care for my Mum, but when you love someone you want to be all things to them. When you can't do this you feel a failure. I don't feel this way anymore. We spend quality time and her care is successful. My health is much better – I didn't think that would happen, I just thought it would get worse and worse.'

Further information

Carers UK has developed an assessment guide to help you plan and think about what is important to you and what kinds of care you provide to see what kinds of support the family might need. Carers use this to help prepare themselves for carers' assessments and it can also be used to help think about personalisation. The guide can be accessed at: www.carersuk.org

Contacts:

Carers UK

CarersLine Telephone: 0808 808 7777
Wednesday and Thursday 10–12 and 2–4
Email: info@carersuk.org

Counsel and Care

Telephone: 0845 300 7585
www.counselandcare.org.uk
For help with making decisions about buying care

Elderly Accommodation Counsel

Telephone: 0800 377 7070
www.housingcare.org

Care Quality Commission

Telephone: 03000 616161
Email: www.cqc.org.uk
For information about the regulator of health and care services.

Acknowledgements

Written by SCIE, in conjunction with Carers UK



Personalisation briefing: Implications for carers

Personalisation: a rough guide tells the personalisation story so far – exploring what it is, where the idea came from and where it sits within wider public service reform. It is freely available online at www.scie.org.uk. This briefing is one of a series explaining the personalisation agenda and what it means for different groups.

Briefings in this series:

At a glance 06: Personalisation briefing for commissioners

At a glance 07: Personalisation briefing for home care providers

At a glance 08: Personalisation briefing for housing providers

At a glance 10: Personalisation briefing for carers

SCIE's At a glance summaries have been developed to help you understand as quickly and easily as possible the important messages and practice advice in SCIE's guides. These summaries will give you an overview of the messages or help direct you to parts of the guide that you may find most useful. You can also use them as training resources in teams or with individuals. We want to ensure that our resources meet your needs and we would welcome your feedback on this summary. Please send comments to info@scie.org.uk, or write to Publications at the address below.

**Social Care
Institute for Excellence**
Goldings House
2 Hay's Lane
London SE1 2HB

tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk

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