



At a glance 15

Personalisation briefing



October 2009

Implications for user-led organisations (ULOs)

Key messages

Personalisation for user-led organisations means:

- people who use services determining their own needs and planning their own support
- recognising that people who use services have skills and expertise as well as support needs
- the opportunity for user-led organisations to take their rightful place in the social care community and marketplace
- the government has said that there should be a user-led organisation in every local authority with responsibility for social care, modelled on existing centres for independent living – the 'Transformation Grant' provides resources for this
- the government has published advice (written with people who use services) outlining the benefits that local authorities can enjoy when they work with user-led organisations
- recognising that user-led organisations need to reach out to all people who may need social care support – including older people and people with mental health problems
- the chance to engage with and support more marginalised people and to promote equality and diversity issues within the local authority.

What is personalisation?

This At a glance briefing examines the implications of the personalisation agenda for user-led organisations.

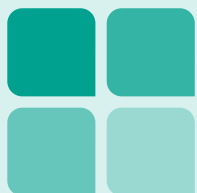
Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when 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 user-led organisations?

User-led Organisations (ULOs) are organisations that are run by and controlled by people who use support services, including disabled people of any impairment, older people, and families and carers. They were set up to promote giving people more choice and control over how their support needs are met. Typically they might provide:

- information and advice
- advocacy and peer support



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- support in using direct payments and/or personal budgets
- support to recruit and employ personal assistants
- assistance with self-assessment
- disability equality training
- support for the implementation of the Disability Equality Duty by public sector organisations in the locality (including consumer audits).

What has the government said about ULOs and personalisation?

One of the recommendations in the Prime Minister's Strategy Unit report *Improving the Life Chances of Disabled People* published in 2005¹ was that there should be a ULO in every local authority area with responsibility for social care, modelled on existing centres for independent living. This commitment has become a key part of the personalisation agenda and was re-stated in the Putting People First concordat² in December 2007:

Support for at least one local user-led organisation and mainstream mechanisms to develop networks which ensure people using services and their families have a collective voice, influencing policy and provision.³

As part of this commitment the government has published an advisory document³ in partnership with people who use services and others which outlines the benefits that local authorities, and their residents, enjoy when they work with user-led organisations. These benefits range

from helping local authorities deliver greater personalisation to improved engagement with seldom-heard population groups.

The Department of Health has devised criteria for what they think these ULOs should look like.⁴ At their most basic they are organisations where the management committee contains at least 60% of people using support services and they provide information and advice for their members. More established ULOs usually have a higher percentage of people using support services on their management committees and provide services such as direct payments and personal budget support schemes.

Support services and co-production

Support services led by people who use services have been found to be particularly effective, especially in helping people manage and use direct payments and personal budgets.^{5,6} This is because ULOs are able to offer peer support – people helping each other on the basis of their own personal experience. Personalisation is about people who use services determining their own needs and planning their own support. Some people will find that easy, most will not and will benefit from the support of others who are in a similar situation.

Moreover, personalisation goes beyond merely establishing the need to involve people who use services in the co-design of services. Increasingly the term 'co-production' is being used in relation to personalisation and transformation of social care.⁷ This approach emphasises that people who use services do not just have needs that must be met but have assets such as skills and expertise to contribute to transformation. User-led organisations are well placed to articulate those assets and forge dynamic relationships with public services to the benefit of all.⁸

1 *Improving the life chances of disabled people*, London 2005: Cabinet Office

2 HM Government (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care* London: HM Government

3 HM Government (2009) *Putting people first: working together with user-led organisations* London: HM Government

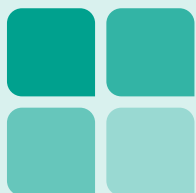
4 www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations

5 Murray K, Tyson A, Murray-Neill R *Increasing the uptake of direct payments* Department of Health 2006

6 Carr S & Robbins D (2009) *The implementation of individual budget schemes in adult social care*

7 Needham, C and Carr, S (2009) *Research briefing 31: Co-production: an emerging evidence base for adult social care*, London: Social Care Institute for Excellence

8 HM Government (2009) *Putting people first: working together with user-led organisations* London: HM Government



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What can ULOs do?

The roll out of personalisation through the Putting People First programme provides ULOs with opportunities to take their rightful place in the social care community. So what can ULOs do?

- make sure your organisation is inclusive – that is, that it is reaching out to all people who need support, including older people in different care settings and people with mental health problems
- make sure you're aware of equality and local diversity issues and try to engage with people who have often been marginalised by traditional services such as some black and minority ethnic people and the lesbian and gay community
- be proactive in making sure your local authority is including you in their personalisation plans including commissioning of services
- draw the attention of your local authority to the DH ULO design criteria, the *Working Together with ULOs* booklet, and the guidance from DH on the use of the transformation grant⁹
- contact your Deputy Regional Director for social care to find out how they are using the resources they have to develop ULOs
- develop your services to meet what people need either within your own organisation or in collaboration with others
- look at the learning coming up from the DH funded ULO action and learning sites¹⁰.

Below are two examples of ULOs who are working with local authorities and developing personalisation support services.

Example 1

Southampton Centre for Independent Living (SCIL) has provided peer based support services to people with direct payments for many years. They are keen to develop this further and embrace the whole personalisation agenda. In 2008 Hampshire County Council set up a commission to look at how best to implement personalisation. SCIL successfully argued that equal weight should be given to the views of people using services as to the views of professionals. People who use services have the experience and the solutions, and do not need professionals to tell them what to do. As a result SCIL are working with Hampshire to develop an expert user panel on personalisation that will mainly consist of people using services.

Example 2

Throughout the In Control and Individual Budget pilots in Norfolk the Norfolk Coalition of Disabled People (NCODP), through its Independent Living Service, worked in partnership with Norfolk Social Services to provide impartial support planning to people with personal budgets who requested it. The service supported all the people on the In Control pilot and two thirds of those on the IB pilot which was aimed at people using mental health services. This support has continued following the introduction of Putting People First. Over the past year the service has expanded providing telephone advice to people with personal budgets who do not feel they need the full support and advice of care managers. Building on the success of the service, this year NCODP plans to provide training on support planning and brokerage to staff from member organisations who are all user-led and other voluntary organisations who work with disabled and older people.

⁹ See Local Authority circular (DH) (2009) 1

¹⁰ This information is available at www.ncil.org.uk and click on the ULO button



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Further information

Cabinet Office (2005) *Improving the life chances of disabled people*, London: Cabinet Office

Carr, S and Robbins, D (2009) *Research briefing 20: The implementation of individual budget schemes in adult social care*, London: Social Care Institute for Excellence

Department of Health (2009) *Local authority circular 1*, London: Department of Health

HM Government (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*, London: HM Government

HM Government (2009) *Putting people first: working together with user-led organisations*, London: HM Government, London: HM Government

Murray, K, Tyson, A and Murray-Neill, R (2006) *Increasing the uptake of direct payments*, London: Department of Health

Needham, C and Carr, S (2009) *Research briefing 31: Co-production: an emerging evidence base for adult social care*, London: Social Care Institute for Excellence

www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations

www.ncil.org.uk

Acknowledgements

Written by SCIE, in conjunction with National Centre for Independent Living

In its report *Personalisation: a rough guide*, the Social Care Institute for Excellence (SCIE) 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

Briefings in this series:

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