At a glance 22

Personalisation briefing

March 2010

Implications for community learning disability staff

Key messages

Personalisation for community learning disability staff means:

- all staff work to develop a partnership between themselves and those who want a personal budget
- staff perform an enabling role which gives people with learning disabilities choice and control
- work to support users to undertake a self assessment, make best use of the Resource Allocation System to secure funding and help people to develop a support plan
- ensuring people have the right information about what they can purchase
- collating unmet needs and giving this information to commissioners to help them develop greater choice in the market
- the task includes the development of community and natural supports to promote people's independence, autonomy and active citizenship
- all staff should have good training, support and development opportunities to enable them to carry out their role.

This At a glance briefing examines the implications of the personalisation agenda for community-based health and social care staff supporting people with a learning disability.

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. It requires a significant transformation of adult social care and jointly provided services 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 in all social care settings and is far wider than 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 community learning disability staff?

Personal budgets and self-directed support

There is emerging evidence, for instance from the IBSEN evaluation of the individual budget pilots, that people with learning disabilities have a lot to gain from increased choice and control over their support arrangements. Support available to date has often been inadequate, unsuitable or

Personalisation briefing: Implications for community learning disability staff

unacceptable. The benefits of choice will be most effectively realised through greater integration of health and social care resources (Glendinning et al 2008.) However, perceptions about risk have sometimes compromised access to, and uptake of, options like direct payments (Carr & Robbins 2009).

The Department of Health is starting to pilot personal health budgets. These will build on the experience of personal budgets in social care, and test ways of giving people greater control over the health services they use.

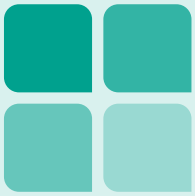
A direct payment is only one way to receive a personal budget. The following points are crucial for understanding how personal budgets work:

- personal budgets should be focused primarily on funding ongoing support and care needs, and normally only considered after looking at relevant preventative and enabling options
- personal budgets can be offered as a direct payment, or as an 'account' managed by the council or a third party
- personal budgets should be implemented within the framework of self-directed support – this involves self-directed assessment, 'up-front' allocation and support planning, to ensure maximum choice and control.

Community learning disability staff have a vital role to play in the successful implementation of personalisation. Care managers and social workers who work within these services provide a statutory role in allocating a personal budget. They will need to have the skills to work in a person-centred way and be aware of the difference between the old and new ways of working. Community learning disability staff will be key in achieving targets set by the Department of Health which aim to have 30 per cent of people on personal budgets by 2011. Workers will need to ensure that support, proper learning and reflection on how to improve the process is on offer. Their role in making best use of finite public sector resources while getting the best for the disabled individual can be difficult and needs to be clearly agreed with their line managers and their adult social care department. Workers will need support, particularly when there is risk involved or criticism from users/families about decisions that have been taken. Staff's role in personalisation involves both statutory duties and the core tasks of developing partnerships with people with learning disabilities, sustaining long term relationships with people who may be in the social care system for all of their lives and undertaking shared decision making with each person.

Example 1

Daniel lived successfully with his carer in south London for 20 years under the adult placement (now called Shared Lives) scheme. Daniel has both a learning disability and mental health problems and needs help with everyday tasks, coping with paper work and keeping to some routines. When his carer, Andrew turned 80 he decided to set up a trust fund and a circle of support for Daniel. After Andrew's death the members of the circle worked with Daniel to apply for a personal budget and administer the trust fund. Daniel's priority was to remain living in the house where he had lived for 20 years and where he had support from neighbours and friends. Daniel is now supported by both pots of funding to have a support worker four days a week, to attend art events (which is his preferred activity) and to carry out a range of domestic chores. He continues to live in his home and pays rent to the trust fund that now owns the house.



Personalisation briefing: Implications for community learning disability staff

Self-directed support is delivered with some differences in each local authority. However all workers, particularly social workers, care managers, support workers and brokers will need to have the skills to:

- enable each disabled person to contribute to a self-directed assessment and support people where possible to lead the process
- work in partnership with the person to achieve an assessment, apply for funding through the Resource Allocation System, and write and implement a support plan
- maximize the choice and control of the person and their family, giving special attention to those who have difficulty communicating or have very complex needs
- understand and help the person choose which method is best for the delivery of the personal budget (options include: the budget to be managed by the person, as the person's account managed by the council, or delivered by a third party such as an independent broker or a legal trust)

Example 2

Alan was keen to work in a local factory on the production line assembling mechanical toys. He was helped to apply for the job and get support through Access to Work. When this support was no longer available, Alan applied for a personal budget. He used the budget to increase the salary of one of his colleagues who became a 'work buddy'. Alan then received support from his colleague to cover a range of tasks. The support was particularly helpful when there was a new task on the assembly line as Alan finds it difficult to adapt to new tasks.

Example 3

Katie is an 18 year old with an outgoing personality. She uses a wheelchair and communicates non-verbally by moving her head and body. She is one of five children and her parents were keen for her to have new experiences and for themselves to have a break. Katie wanted to do more things common to all 18 year olds, such as going out at the weekend and shopping for fashionable clothing.

She applied for, and was given, a direct payment and her family recruited local university students to support her. With paid support from people her own age she was able to do the things that her family found difficult and was more able to enjoy life and be helped to apply to college.

- be clear that the disabled person does not have to become an employer of staff if they don't wish to take this on and they can get help from a broker to help them navigate the system
- be clear that the person can purchase personal care, practical assistance, support to access education, leisure and/or work or whatever else will help the outcomes agreed in the care plan
- develop a circle of support to bring together people to assist the person to achieve their goals, making use of natural supports in the community and extending their social network
- bring together other sources of funding such as the Independent Living Fund to increase available resources.

Personalisation briefing: Implications for community learning disability staff

A key role for all staff is to develop good systems of information so that people with learning disabilities can have choice, and recognise that they are consumers with purchasing power. Staff can be instrumental in identifying gaps in services that disabled people are seeking to purchase but are not available. This information is important to pass on to local commissioners to assist in developing the local market, including third sector organisations. Many people with learning disabilities will need support from an agreed person/agency to hire their own worker, to cope with salary payments, national insurance and carry out all the functions of an employer.

Successful personalisation will depend on community-based staff having:

- an increased focus on outcomes
- doing less crisis work and more long term planning e.g. helping learning disabled adults to move to their own home before parents can no longer offer support
- a balanced view between risk taking (which promotes development) and safeguarding the person
- a commitment to helping people overcome a sense of powerlessness
- the ability to challenge risk averse cultures
- an awareness that their own continuous learning and support are essential to getting good outcomes for all.

The success of personalisation and mechanisms like personal budgets will depend on a significant culture shift in local authorities. Changes in culture and practice can only happen if staff at the front line have the confidence and take responsibility to challenge and change traditional methods of working. Staff will need to demonstrate new ways to take and manage risk, let go of some power, focus on prevention and find community-based solutions. In parallel, senior managers, policy makers and local politicians will need to support these changes and learn lessons from the new processes that are in place. Lessons learned from crisis situations should be used as a means of improving the process rather than creating restrictions or curtailing the autonomy of frontline staff.

Workers in the service will have an important role in making the process non-bureaucratic and accessible to people with learning disabilities, as well as contributing to methods of reviewing the process and monitoring satisfaction levels of those holding personal budgets.

Where personalisation works well, the host organisation has a strong culture of seeing people with learning disabilities and their families as leaders and experts through experience; employ them as trainers and service providers and uses their skills to influence elected members and partnership boards.

Staff working to help implement personalisation have a real opportunity to influence change, improve the quality of life for people with learning disabilities and help people through creative means to make best use of the important changes now being offered.

Further information

Carr, S. & Robbins, D. (2009) *Research briefing 20: The implementation of individual budget schemes in adult social care*, London:SCIE

Department of Health/ADASS (2009) *Making progress with Putting People First: self-directed support* London: Department of Health/ADASS/IDeA/LGA

Glendinning, C. et al (2008) *The national evaluation of the individual budget pilot programme: experiences and implications for care coordinators and managers*, York: Social Policy Research Unit, University of York

Independence, Choice and Risk; a guide to best practice in supported decision making. Available at **www.dh.gov.uk**

The personalisation toolkit
www.personalisation.org.uk

In Control **www.in-control.org.uk**

Acknowledgements

Written by SCIE, in conjunction with The Foundation for People with Learning Disabilities.

Personalisation briefing: Implications for community learning disability staff

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: Implications for commissioners

At a glance 07: Personalisation briefing: Implications for home care providers

At a glance 08: Personalisation briefing: Implications for housing providers

At a glance 10: Personalisation briefing: Implications for carers

At a glance 12: Personalisation briefing: Implications for advocacy workers

At a glance 13: Personalisation briefing: Implications for voluntary sector service providers

At a glance 14: Personalisation briefing: Implications for personal assistants (PAs)

At a glance 15: Personalisation briefing: Implications for user-led organisations (ULOs)

At a glance 17: Personalisation briefing: Implications for residential care homes

At a glance 18: Personalisation briefing: Implications for community mental health services

At a glance 21: Personalisation briefing: Implications for people with autistic spectrum conditions and their family carers

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