



NHS Evidence – learning disabilities

Personalisation & adults with learning disabilities: an annotated guide to the literature



Introduction

This brief guide aims to identify and briefly summarise recent literature relevant to supporting adults with learning disabilities in the context of the personalisation agenda in England. It is not a comprehensive or systematic review of the literature, but should provide a broad based starting point for people wanting to put the current personalisation agenda in context and find tools and documents to help explain the key concepts and terms.

A note on terminology

A number of key terms appear to be used, sometimes interchangeably, in the literature.

The following brief glossary may help to clarify some of these terms.



Personalisation – this term is coined in the green paper *Independence, Well being and Choice*, and refers to a new way of thinking about public services and social care, one which starts with the person with social care needs rather than the social care service. It could be described as the policy direction or approach.

Transformation - the process by which organisations will change their systems and procedures to enable personalised responses to people with social care needs.

Self-Directed Support – system through which personalised services will be delivered, including supported self assessment to identify an indicative budget, making a plan organising support and getting this signed off by the funding local authority.

In Control – an independent company registered as a charity which began its life as a project in 2003 in order to look at new ways of organising the social care system to deliver more personalised outcomes for people.

Individualised Budget – a combination of funding sources associated with one person (e.g. Individual Budgets pilot scheme included funding from Supporting People, Access to Work, the Disabled Facilities Grant, the Independent Living Fund and the Integrated Community Equipment Services fund).

Personal Budget – social care funding allocated to an individual with assessed social needs that can be used for the purchase of supports to meet outcomes identified in the individual support plan. A personal budget can be looked after by the disabled person themselves, the person's Agent, a Trust set up to act for the disabled person, an independent broker, a service provider or a Care Manager.

Direct Payments – cash payment paid to somebody with social care needs to enable them to purchase support to meet their needs. It must be used to achieve outcomes recorded in the Support



Plan. Direct payments cannot be used to purchase residential care, services provided by a health authority or support from relative living in the same household.

Support Brokerage – the role of helping people plan and organise any support they need. A broker will not be involved in 'rationing' resources or in providing supports. In control defined brokerage as a 'function'.

The Literature

1. Legislation, Policy and Guidance

- a. **Independence, Well Being and Choice (Department of Health 2005)** Green paper setting out a new vision of adult social care, which identified direct payments and individual budgets as mechanisms for enabling adults with social care needs to take greater control of their lives. <http://bit.ly/dgcOc1>
- b. **Our Health, Our Care, Our Say (Department of Health 2006)** White Paper confirming the vision set out in Independence, Choice and Control. Sets out a series of measures to ensure services are flexible and responsive to individual needs, putting people more in control and shifting to a greater emphasis on prevention - fitting services around people not people around services. <http://bit.ly/9aLuh6>
- c. **Putting People First (Ministers, local government, NHS, social care, professional and regulatory organisations 2007)** Cross Government concordat with a shared ambition to put people first through a radical reform of public services, enabling people to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, well-being and dignity. Putting People First sets out shared aims and values for the transformation of adult social care to transform people's experience of local support and services. <http://bit.ly/17I5Ke>
- d. **Health and Social Care Act (2008)** The Health and Social Care Bill was introduced into Parliament on 15 November 2007. It contains significant measures to modernise and integrate health and social care. The Health and Social Care Act 2008 received Royal assent on 22 July 2008. <http://bit.ly/cTF0ho>. The act introduces the new Care Quality Commission <http://www.cqc.org.uk/>.
- e. **Putting people first - working together with user led organisations (HM Government 2009)** Outlines the benefits of working with user-led organisations, including helping local authorities deliver greater personalisation to improved engagement with hard-to-reach population groups. <http://bit.ly/dtB5Cr>
- f. **Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care - guidance on eligibility criteria for adult social care (Department of Health 2010)** Guidance issued under section 7(1) of the Local Authority Social Services Act 1970. Replaces Fair Access to Care Services (guidance on eligibility criteria for adult social care issued in 2003). This guidance will need to be applied from April 2010. <http://bit.ly/cq59Fp>





- g. **Personalisation through person centred planning (Department of Health 2010)** This joint good practice guidance published by the Putting People First and Valuing People Now teams has been developed to help local areas understand how person-centred planning can help to deliver Putting People First. It is one of the commitments in Valuing People Now. It includes a range of tools and good practice examples on person centred planning and support planning to help give people more choice and control over their lives. <http://bit.ly/dn2KMm>
- h. **Personal Budgets: Council Commissioned Services: Advice Note (Association of Directors of Adult Social Services 2010)** ADASS advice on how personal budgets can work well for people who use council-commissioned services rather than a direct payment. <http://bit.ly/d4y7aX>

2. Reviews & Evaluations

- a. **Evaluation of the Individual Budgets Pilot Programme: Final Report**, Glendinning C et al. (2008) Individual budgets (IBs) were piloted in 13 local authorities as a new way of providing support for people with social care needs. This evaluation is the first robust UK study of the implementation and impact of personalisation approaches in social care. <http://bit.ly/9or3ys>
- b. **Personalisation and learning disabilities: A review of evidence on advocacy and its practice for people with learning disabilities and high support needs**, Lawton A (2009) Evidence suggests that people with learning disabilities and high support needs are likely to be left behind in social care services provision while those who are more independent have more choice and control. This review aims to identify and consolidate available evidence of progress and innovation in advocacy practice in relation to people with learning disabilities and high support needs. <http://bit.ly/9aNelh>
- c. **In Control Self-Directed Support Evaluation reports** This 'in control' page links to reports evaluating the effect of Self-Directed Support on the lives of people who have Personal Budgets, their families and the staff who support them in a number of areas of the UK. <http://bit.ly/9eptq2>
- d. **In Control Reports**
 - i. **A report on in Control's first phase 2003-2005.** <http://bit.ly/9ynlN0>
 - ii. **An evaluation of and report on in Control's work 2005-2007.** <http://bit.ly/boQtd5>
 - iii. **A report on In Control's Third Phase. Evaluation and learning 2008-2009.** <http://bit.ly/d8EBL7>
- e. **Doing it Your Way: The story of self directed support in Worcestershire** (2009) The story of 73 people with a Personal Budget of which 46 had their plans agreed and were spending their money on supports to achieve their outcomes. <http://bit.ly/9sLyRE>



3. Resources

- a. **Personalisation toolkit** An on-line resource to support councils to begin to plan and deliver the transformation of their social care systems, as set out in Putting People First. The focus is on learning from the Individual Budget Pilot programme. <http://bit.ly/awvDoK>



- b. **Progress for Providers Self Assessment Tool** Simple self assessment tool to help providers think about their progress in responding to the personalisation agenda focusing on delivering personalised, individually costed services and individual service funds. <http://bit.ly/9q0Wnk>
- c. **My life, my budget - board game** My Life, My Budget is a board game for people with learning difficulties and other disabilities who want to know more about Personal Budgets. It walks the player through the seven steps to getting a Personal Budget. <http://bit.ly/c2uilw>
- d. **The National Brokerage Network** a 'Network' of Networks' set up as an information exchange. <http://bit.ly/dfth0i>
- e. **Developing Support Brokerage Discussion Paper** (in Control) <http://bit.ly/c0XPxf> and **The Emergence of the Independent Support Broker Role** (NDTi). <http://bit.ly/aer79E>

4. Web links

- a. **Department of Health Personalisation site** (currently under review as a result of the recent change of Government). <http://bit.ly/cp4xPh>
- b. **In Control** site containing vast amount of information on the development of self-directed support and detailed discussion papers on each step in the seven step process. <http://bit.ly/8ASpz>
- c. **Social Care Institute of Excellence personalisation microsite** including interactive guides, elearning and briefings. <http://bit.ly/d60z26>