

Dementia Choices

PROJECT SUMMARY FOR STAKEHOLDERS

Dementia Choices is a two year Mental Health Foundation project which began in April 2009 and is funded through the Department of Health's Innovation, Excellence and Service Development Third Sector Investment programme

The overall aim of ***Dementia Choices*** is:

“To explore, support and promote different forms of self-directed support, including direct payments, individual budgets and personal budgets, for people living with dementia and their carers”

Specifically we aim to:

1. Explore and promote what people living with dementia might want from the different forms of self-directed support
2. Explore and promote the kind of information on self-directed support people living with dementia, or their carers, need (particularly if the person may lack mental capacity for some decisions, or wish to make plans in case they lose capacity in the future)
3. Explore and identify the appropriate safeguards to ensure that people living with dementia who lack mental capacity can still safely benefit from self-directed support
4. Enable stakeholders to understand the barriers preventing the take up of the different forms of self-directed support
5. Support and promote the development of different ways of delivering support to overcome these barriers

How will the world be different as a result of Dementia Choices?

We anticipate the following outcomes as a result of this work:

1. People living with dementia and their carers will have experienced real choice and control over their lives, with appropriate safeguards, and will have received truly personalised support.
2. There will be a good level of awareness and understanding of the barriers and benefits of the different forms of self-directed support (including the new legal powers that support people to plan ahead and develop self directed support by proxy) amongst the following groups: (A) people living with dementia, (B) their carers and (C) the organisations supporting them.
3. There will be a high level of satisfaction among people living with dementia and their carers with planning and arranging the ongoing support they receive via the different forms of self-directed support.
4. Specific examples and stories of real experiences, both positive and negative, in the use of the different forms of self-directed support will have been shared.
5. Local pilot site stakeholders will have identified, explored and found solutions to the existing barriers to people living with dementia (and their carers) taking up the different forms of self-directed support.

6. Health care services will have received the learning from *Dementia Choices* to inform the delivery of self-directed support programmes

SELF-DIRECTED SUPPORT - *What do we mean by self-directed support?* 'Self-directed support' is a term grounded within the work of In Control dating back to 2003. Self-directed support has become an increasingly accepted term which relates to the variety of approaches to creating personalised care, where people are in control of their support or life. Self-directed support is characterized by the following:

- The support is controlled by the individual
- The level of support is agreed in a fair, open and flexible way
- Any additional help needed to plan, specify and find support should be provided by people who are as close to the individual as possible
- The individual should control the financial resources for their support in a way they choose.
- All of the practices should be carried out in accordance with an agreed set of ethical principles.

Self-directed support is one of many approaches which aim to create and deliver personalisation. Other approaches include person-centred planning, person-centred care, person-centred support and independent living.

PERSONALISATION - The term 'personalisation' is a relatively new term but is now at the centre of Government policy in social care, as well as some areas of health care. It means starting with the individual as a person with strengths and preferences who may have a network of support and resources, which can include family and friends. They may have their own funding sources or be eligible for state funding. Personalisation reinforces the idea that the individual is best placed to know what they need and how those needs can best be met. It means that people can be responsible for themselves and can make their own decisions about what they require, but that they should also have information and support to enable them to do so. In this way services should respond to the individual instead of the person having to fit with the service. Personalisation is about giving people much more choice and control over their lives.

Dementia Choices has a particular focus within the larger 'personalisation' agenda outlined above. Specifically it will be exploring the different forms of self-directed support and approaches to personalised social care including direct payments, individual budgets and personal budgets.

DIRECT PAYMENTS - A 'direct payment' is a means-tested cash payment made in place of regular social service provision to an individual who has been assessed as needing support, the money included in a direct payment only applies to social services.

INDIVIDUAL BUDGETS -An 'individual budget' sets an overall budget for a range of services, not just from social care, from which the individual may choose to receive as cash or services or a mixture of both, individual budgets combine resources from different funding streams to which an assessed individual is entitled (currently these are: local authority adult social care, integrated community equipment services, disabled facilities grants, supporting people for housing-related support, access to work and independent living fund).

PERSONAL BUDGET -Originally the term 'personal budget' only applied to social care funding but now it is often used interchangeably with 'individual budget'. A personal budget is the funding given to someone after they have been assessed which should meet their needs. These budgets give people a transparent allocation of money and the right to choose how this is managed and spent.

PERSONAL HEALTH BUDGETS - The Department of Health are now piloting 'personal health budgets' with a wide range of Primary Care Trusts looking to build on the experience with individual budgets in social care to test personal health budgets as a way of giving people greater control over the health services they use. Personal health budgets are not under the specific remit of *Dementia Choices* but it is anticipated that the *Dementia Choices* pilot sites and the personal health budgets pilot sites will have a lot to learn and share with each other.

(Information adapted from Personalisation: a rough guide, report 20, Social Care Institute for Excellence (SCIE),

Thus broadly the focus of *Dementia Choices* is on the individuals who are eligible for state funding. Where we refer to carers, we are specifically referring to carers directly involved in the support planning process with people living with dementia (by proxy or by third party) rather than looking in any detail at carers receiving and using their own self-directed support, which they may be eligible for in their own right. *Dementia Choices* is starting at a time when the National Dementia Strategy is being implemented, *Dementia Choices* is not formally part of the pilot site and wider implementation work directly connected with the strategy although will have much to share with the implementation of the strategy in order to help improve the choices people living with dementia, and their cares, have in their lives. *Dementia Choices* is also not specifically going to address the 'market' or developing the supply of personalised social care services.

For more information on the background, development and resource materials related to self-directed support please visit the In Control website: www.in-control.org.uk

Dementia Choices – why is the project important?

Evidence has consistently shown a relatively low take up of direct payments among older people as compared to other groups and compared to the proportion of older people in the population. In 2005-6 local authority expenditure on older people accounted for over 60% of total expenditure but only 2.7% of local authority expenditure went on direct payments for older people, as compared to 22% on people with physical disabilities who accounted for less than 10% of the total local authority expenditure (*State of Social Care in England 2006-7*, CSCI 2008).

Up until 2008 legislation has prevented people who lack mental capacity to consent to direct payments or individual budgets – this means the take up of direct payments among people with dementia has been almost non-existent. Further obstacles preventing the uptake has also included the bureaucracy involved, social services not actively promoting direct payments for older people as they have done for other groups and a lack of information and genuine choice for older people. Direct payments (and personal budgets

or individual budgets used for social care purposes) are by definition a 'means-tested' payment and thus access to them is dependent on fulfilling the eligibility criteria as defined by the Fair Access to Care Services, many older people in particular, labelled as 'self-funders' have therefore not had access to direct payments and have been privately arranging their social care services. Direct payments are also distinct and different from Attendance allowance/Disability Living Allowance which are welfare benefits to which many people living with dementia will become entitled to and which have no formal restriction on what they can be spent on.

The IBSEN evaluation of the Individual Budgets pilot programme showed that personal budgets were generally welcomed by many individuals, including older people, because they gave them more control over their lives, but older people reported lower-psychological well-being with individual budgets, perhaps because they felt the processes of planning and managing their own support burdensome (*Evaluation of the Individual Budgets Pilot Programme: Final Report*. 2008. Individual Budgets Evaluation Network (IBSEN), SPRU, University of York). However in the Department of Health's response to the IBSEN evaluation it pointed out that the research also showed that once these barriers are overcome, with the right support and cultural change, personal budgets are a positive option for older people (*Moving Forward: Using the Learning from the Individual Budget Pilots*. 2008. Department of Health). The Department of Health made it clear that they are keen '*that strong efforts are needed to make sure older people can benefit fully from self-directed support.*' There are a number of resources and guides to assist this happening. However there is very little mention in these resources and guides, or in the IBSEN evaluation of how people with dementia and their carers can potentially take advantage of personal budgets. *Dementia Choices* aims to provide that information in an appropriate and accessible way because it will be shaped by the people who are using it.

The Mental Health Foundation also has its own evidence from a telephone survey it carried out two years ago of some local authorities which involved making enquires about direct payments for people with early onset dementia (i.e. under the age of 65) through 'cold calling'. This revealed some interesting results. 40 local authorities were telephoned. Upon getting through to reception/switchboard to enquire about direct payments only 5 connected straight to the correct department, 24 connected to the finance department and 11 asked for further information to help. Having reached adult services in only 34 of the authorities, 4 still required further information to connect to the person responsible for direct payments. On reaching the lead person responsible for direct payments nearly half had never heard of early onset dementia (despite the prevalence figures suggesting that there could be well over 100 people with the condition in their area). This sample suggests that much work is needed in this field if people with dementia are to benefit from personal budgets.

There are approximately 580,000 people with dementia in England and this figure is set to rise with an ageing population and people living longer (Dementia UK, 2007). With the Health & Social Care Act 2008 allowing direct payments to be provided for the first time to people who lack the capacity to consent there will be much greater opportunity for people with dementia and their carers to benefit from personal budgets (NB: at the time of writing this section of the Health & Social Care Act 2008 has not yet come into force). These opportunities will also benefit from the new legal powers for planning ahead created under the Mental Capacity Act 2005.

***Dementia Choices* has a detailed plan of activities.**

We will:

1. Identify and help develop pilot sites that aim to enable people living with dementia and their carers to understand, access and explore the barriers and benefits of the different forms of self-directed support.
2. Develop and provide information to promote a more flexible approach to self-directed support which encourages professionals to plan and commission services accordingly.
3. Produce information identifying the barriers which currently prevent the uptake of the different forms of self-directed support for people living with dementia and their carers.
4. Nationally disseminate the learning, information and advice from the pilot sites identifying the possible solutions to overcoming these barriers.
5. Facilitate a *Dementia Choices* Network for learning, and information exchange
6. Organise and facilitate a *Dementia Choices* reference group of key stakeholders
7. Support the development of local networks of stakeholders in the pilot sites
8. Hold a national awareness raising event in year one of the project and an end of project event in year two

***Dementia Choices* – project management**

Dementia Choices is part of the Foundation's mental health research and development programme. The project lead is Toby Williamson, Head of Development, who is also responsible for work on older people's mental health at the Foundation. The project is currently employing Neil Mapes, a project consultant, to manage the initial stages of the project. Neil has extensive experience of working with people with dementia and has been the project co-ordinator for Age Concern's Mental Capacity Advocacy Project.

The funding of this project only allows the work to be carried out in England but we anticipate there will be much to share with developments taking place in other countries.

***Dementia choices* will be producing**

- Information, advice and guidance for individuals, groups and social care providers on different forms of self-directed support with people living with dementia and their carers.
- Innovative service improvement interventions and development which enable truly personalised support for people with dementia and their carers in the pilot sites.

***Dementia choices* – connecting with us**

There are a variety of ways in which you can connect with this important and timely project.

Potential pilot sites: we will be selecting a minimum of two pilot sites to explore and develop this work in the summer, to begin their work in October 2009. Pilot site organisations may be, for example, small community groups, local branches of national voluntary organisations, statutory local service providers and partnerships where

organisations can work together to fulfill the remit of *Dementia Choices*. We will be looking to select at least one pilot site which can deliver this work in diverse communities or in a rural location and as many pilot sites as we are able to successfully support to maximise the learning from this work. For more information on the selection criteria and process please contact Neil Mapes, or download the Expression of Interest document from the *Dementia Choices* web page.

Sharing good practice with us: Perhaps you have a key piece of advice or a valuable resource to share with us to help us deliver this work. If so please contact us.

***Dementia Choices* Network:** will be established as part of this work to share learning and to be a place in which up to date information can be exchanged. This network will have a web based focus but will involve face-face opportunities for learning too. If you are interested in being part of this innovative network please contact us.

***Dementia Choices* Reference Group:** will also be established as a key support structure for this project. This group will incorporate key national stakeholders including people with dementia and their carers. This group will meet twice a year to inform the delivery of this work but will also be part of a wider 'virtual' group to enable the project to receive expert advice and guidance. The *Dementia Choices* network will have opportunities to feed into this group.

***Dementia Choices* events:** the project will be holding an event in year one and an event in year two to increase the awareness and understanding of the issues and promote the development of self-directed support for people living with dementia and their carers. Information about these events will be available via the Mental Health Foundation website. Please visit the website for further information on these events. If you would like a representative from *Dementia Choices* to speak at or run a workshop at your event then please contact us.

The Mental Health Foundation is the leading UK charity working in mental health and learning disabilities. The Foundation is unique in bringing together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle challenging issues and try different approaches, many of them led by local citizens. The Mental Health Foundation's mission is to "*put research into practice to help people survive, recover from and prevent mental health problems.*"

Dementia Choices is being supported and delivered by a project team at the Foundation consisting of Toby Williamson, Neil Mapes and Rachel Downing.

Toby Williamson is the Project Lead for *Dementia Choices* and takes overall responsibility for this work in his role as Head of Development at the Mental Health Foundation. Toby is the Chair of the *Dementia Choices* reference group which is a group consisting of external experts (including a person with dementia and carers) which meets twice a year, to advise us on the delivery of this work.

Neil Mapes is the Project Consultant working on *Dementia Choices*, Neil's role includes developing documentation, direct liaison and support of the pilot sites, conducting an

evaluation and drafting information and guidance as the project develops.

Rachel Downing has just joined the Foundation for a year long placement as part of a graduate training programme in social care management, run by the National Skills Academy for Social Care. Rachel's role includes assisting in the development of the Dementia Choices Network and compiling the Dementia Choices Network Newsletter

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Where can I get more information?

There are an increasing number of important publications of relevance to this work, below readers are directed to some of the latest and important publications. In addition a list of dementia publications produced by the Mental Health Foundation has been included to highlight our work undertaken in this field to date.

Further reading

- **Alzheimer's Society publications catalogue** - details all the factsheets, booklets, leaflets and publications available: including the key report *Dementia UK* published in 2007, all are downloadable from www.alzheimers.org.uk
- **Social Care Institute for Excellence (SCIE) publications and resource list** - includes a vast array of information, readers are directed to research Briefing 31 (March 09) "Co-production: an emerging evidence base for adult social care transformation", and to Research Briefing 20 (March 09) "The implementation of individual budget schemes in adult social care", Report 20 "Personalisation: a rough guide" and to the discussion paper "Will community-based support services make direct payments a viable option for individuals from black and minority ethnic service users and carers?" www.scie.org.uk
- **Age Concern and Help the Aged** – have a variety of publications of relevance including Factsheet 24 "Direct payments from social services" (March 2008), www.ageconcern.org.uk. The Age Concern report called "Information, advice, advocacy, support planning and brokerage – self-directed support and older people" is recommended to readers.
- **Economic and Social Research Council (ESRC)** - Seminar series on the "Impact of personal budgets on third sector providers of social care". (Feb 09) www.esrcsocietytoday.ac.uk
- **ADASS and Local Government Association** Survey (April 2009) "Putting people first: Measuring progress" www.adss.org.uk
- **King's Fund** – March 2009 Briefing "Funding adult social care in England" www.kingsfund.org.uk
- **Department of Health** - Putting People First, Transforming Adult Social Care. March 2009 Response to the consultation on the extension and revision of Direct Payments Regulations. www.dh.gov.uk
- **NICE guideline 42** - Dementia: Supporting people with dementia and their carers in health and social care, www.nice.org.uk

- **British Journal of Social Work** (2008) 1-23, towards integrated participation: involving seldom heard users of social care services by Hernandez, Robson and Sampson.

Mental Health Foundation - dementia publications

- **Carers checklist** (1998) - This an outcome measure for people with dementia and their carers. An easy to use scale, in the form of a questionnaire, which can be used to assess the needs of people with dementia and their carers, and to evaluate the outcomes of service intervention.
- **Dementia Advice and Support Update** (2001) - Update briefing on nationwide early intervention services for people with dementia and their families. In April 2001, the Mental Health Foundation launched a UK wide service development project entitled the Dementia Advice and Support Service (DASS). The project represents the Foundation's first substantive development in the field of mental health of older people; it is unique in its range and remit and has considerable potential to contribute positively to the improvement of services for people with dementia and their families.
- **Dementia Diagnosis Update** (2001) - Update briefing on the effect of being given a diagnosis of dementia.
- **Tell me the truth** (2001) — A report on the effects of being told the diagnosis of dementia from the perspective of the person with dementia.
- **Dementia. Ethnicity and Culture Update** (2003) - Update briefing on the findings of a research and service development seminar held by the Foundation to explore the research and service development challenges relating to ethnic minority elders with dementia.
- **First Signs** (2004) - This report is a celebration of the Mental Health Foundation's Dementia Advice and Support Service (DASS) UK Project. It outlines the background to the project, touching on the policy and research context of early intervention in dementia services.
- **Culture and Care in Dementia** (2004) - Report based on action research with the Asian Community in North West Kent, as well as service providers and professionals. Of interest to anyone interested in dementia, service development for Black and Minority Ethnic Groups, conducting action research with Black and Minority Ethnic Groups, and awareness-raising campaigns in Asian communities
- **Becoming a carer** (2005) - A booklet about looking after someone with dementia. It explains some of the basic facts about dementia, gives ideas on where you can get practical and emotional support, offers advice on how to plan for the future, and provides some tips on caring for people with dementia.
- **The Milk's in the Oven** (2005) - A revised and updated version of the booklet originally written by Lizi Hann in 1998 explaining how people with dementia behave and feel, and aiming to provide young people with information about the illness and how to cope with

knowing someone who was dementia. There are a number of exercises in the booklet which make it ideal for us in the classroom, as part of a PSHE lesson.

- **Still going strong: A guide to living with dementia** (2005) - This booklet explains some of the basic facts about dementia, gives ideas on where you can get practical and emotional help, offers advice on planning the future, and details some strategies which other people have used to cope with dementia.

- **Getting on with living** (2007) - The focus of this report is on the provision of information, social and emotional support, post-diagnosis, for people with dementia and their immediate supporters. This guide is intended primarily for managers and senior practitioners in health and social care who are concerned with setting up, operation and development of early dementia support services. It will be of interest to commissioners, service providers and anyone actively involved in service development.

Appendix: Additional resources and reading

In addition to the resources and references highlighted above we conducted a further desk top review of the literature connected to personalisation and dementia during September 2009 and have collated a number of important further references, reports and reading.

Contracting for personalised outcomes: learning from emerging practice (August 2009)

Department of Health document on personalised budgets there are several useful case studies of how six local authorities have begun to implement personalised services.

http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_adv_ice/CFPO.pdf -

Self-directed support: direct payments, personal budgets and individual budgets (July 2009)

Self directed support fact-sheet containing all the basic information on direct payments and self-directed support.

http://www.ageconcern.org.uk/AgeConcern/Documents/FS24Self_directed_support.pdf

Personalisation, choice and empowerment: a political and economic reality check. Dr Simon Griffiths, Social Market Foundation (May 2009)

An examination of the political and economic implications of personalisation, which places personalisation within the wider empowerment agenda.

<http://smf.smf.co.uk/assets/files/Personalisation%20paper%20for%20ILA.pdf>

“Putting People First: One Year On” (March 2009) A speech by Phil Hope, Minister for State Care Services, a review of the progress made in the “putting people first” philosophy and an outline of the next steps to putting personalisation into practice.

http://www.dh.gov.uk/en/News/Speeches/DH_096954

Peer Support and Personalisation (Dec 2008) A report by the National Council for Assisted Living for the Department of Health, examines the role that peer support can play in implementing a personalisation agenda. The report contains examples from the independent living movement of how peer support can assist self directed payment.

http://www.ncil.org.uk/uploads/pdf/872661770_Peer%20support%20Final%201.doc

The personalisation of adult social care in rural areas. Commission for Rural Communities Manthorpe, J. and Stevens, M (August 2008)

A report examining the impact of an ageing population in a rural setting on adult social care and how it can be developed.

www.ruralcommunities.gov.uk/publications/crc78thepersonalisationofadultsocialcareinruralareas

Declaration of Independence Joanna Lyall February (2008) An article from the guardian with five case studies of how personal budgets have affected five different service users <http://www.guardian.co.uk/society/2008/feb/06/8>

Department of Health Local Authority Circular: Transforming Social Care (January 2008)

Sets out the support for the transformation of Social care through the Social Care Green paper- "our health, our care, our say: a new direction for community services". Identifies some of the challenges faced due to personalisation and highlights how the department of health intends to support change

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_082139.pdf.

Evaluation of the Individual Budgets Pilot Programme: Final Report. Glendinning, C., Challis, D., Fernández, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008)

The evaluation of the individual budgets pilots in England, the report outlines the outcomes and highlights the challenges faced by the pilot sites.

<http://php.york.ac.uk/inst/spru/pubs/1119>

Direct payments and social care commissioning: The challenges for local authorities, Janet Leece, (July 2006) This article examines the challenges that local authorities face implementing direct payments, including how to plan for the whole community and the need to develop a new workforce of personal assistants.

<http://www.dhcarenetworks.org.uk/BetterCommissioning/Commissioning-book/Chapter3CommissioningwithServiceUsersandCarers/3.11Directpaymentsandsocialarecommissioningthechallengesforlocalauthorities>

Implementing direct payments in mental health Karen Newbigging with Janice Lowe, (February 2005)

A report, by the Joseph Rowntree Foundation of how the uptake of direct payments by people experiencing mental health problems can be increased which highlights the barriers that can prevent people exploring personal budgets.

<http://www.jrf.org.uk/publications/implementing-direct-payments-mental-health>

It pays dividends: direct payments and older people. Clark, H., Gough, H. and McFarlane, A. (2004) British Journal of Social Work. A study that explores three schemes and the experiences of 41 older people who received direct payments, the article analyses not only the experiences of service users but also those of service providers

http://bjsw.oxfordjournals.org/cgi/pdf_extract/35/8/1419

The Department of Health Personalisation Toolkit- Older People

<http://www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/Olderpeople> A Department of Health network on personalisation with regular updates on the latest research, news and reports, it would be advisable to join the network so you can receive the latest information.

Links to relevant legislation

Health and Social Care Act 2008

http://www.opsi.gov.uk/acts/acts2008/ukpga_20080014_en_12

Section 146 amending Section 57 of the 2001 act

Health and Social Care Act 2001

http://www.opsi.gov.uk/Acts/acts2001/ukpga_20010015_en_1

Section 57 and 59 (interpretation guidelines)