

***Dementia Choices* Evaluation Framework – Aims and Outcomes, Objectives and Outputs**

Background and purpose

This evaluation framework has been initiated by Neil Mapes. The detail is based within the accepted good practice by the Charities Evaluation Services. For more information and for various downloads please visit: <http://www.ces-vol.org.uk>. The purpose of this document is to enable all people connected to the work of *Dementia Choices* to be clear about:

- why this project is important
- the changes we want to see as a result of this project
- the activities we are planning to bring about these changes
- the monitoring and evaluation
- the impact of the work

Definitions

It is important to begin by defining key words and terms that quite often are misunderstood. These misunderstandings and confusion between terms often hinders project management and performance.

OVERALL AIM	Why the project exists and the broad effect that it wants to have. A summary of the overall difference it wants to make. Projects have an overall aim, at an organizational level this would be called a mission and would have the same definition.
SPECIFIC AIMS	Particular changes or differences the project or organisation plans to bring about for its users. Specific aims break down the overall aim into a series of particular changes or differences that, if they all happen, achieve the overall aim.
OUTCOMES	The changes, benefits, learning or other effects that result from what the project or organisation makes, offers or provides. Outcomes are linked to aims.
OBJECTIVES	The areas of activity or practical steps a project or organisation plans to accomplish its aims.
OUTPUTS	Products, services or facilities that result from a project's or organisation's activities. Outputs are linked to Objectives.

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 carers, 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

Overall aim of *Dementia Choices*

“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.”

Specific aims of *Dementia Choices*

In order to explore, support and promote the different forms of self-directed support for people living with dementia and their carers we will:

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

Outcomes of *Dementia Choices*

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

Objectives of *Dementia Choices*

What practical steps will we plan and take to meet our aims? 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.

Outputs of *Dementia Choices*

- 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.

Monitoring and evaluation

Toby Williamson (project lead) and Neil Mapes (project consultant) will work with the *Dementia Choices* reference group, the local pilot project teams and networks, and the Foundation's research team to develop simple but appropriate evaluation methods.

These will include:

- Basic quantitative data and information about individuals and organisations that are involved in the project
- Qualitative and informal data which ‘tells the story’ and captures people’s views
- Use of an iterative model to develop the information and guidance via a cycle of local consultation, developments and re-evaluation by participants.
- A similar iterative model used with practitioners, service developers and commissioners to support, where necessary, service improvements in the pilot site areas to overcome any obstacles to increased take up of the different forms of self-directed support..
- Feedback from local sites, reference group and from the local and national networks about the perceived usefulness of the information and guidance, and any other activities that may have occurred in the pilot sites and the general experience of participating in the project. This will be feedback via contact with the project lead and consultant, regular meetings, and online communication.

The tables below provide a framework to guide the detail of this monitoring and evaluation reporting

AIMS
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. Support and promote the development of different ways of delivering support to overcome these barriers
5. Enable stakeholders to understand the barriers preventing the take up of the different forms of self-directed support

OUTCOMES	OUTCOME INDICATORS	INFORMATION COLLECTION METHODS	WHEN	REPORTING METHODS
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	Qualitative quotes and real life stories	Qualitative data gathering Local consultation events	Mar 2010 Sep 2010 Mar 2011	Progress reports Final report
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.	Qualitative quotes and real life stories Questionnaire data	Consultation groups Local Networks Questionnaires	Mar 2010 Sep 2010 Mar 2011	Progress reports Final report
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.	Qualitative quotes Real life stories Questionnaire data	Consultation groups Local networks Questionnaires	Mar 2010 Sep 2010 Mar 2011	Progress reports Final report
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.	Case studies Dissemination methods	Consultation groups Local Networks DC Network	Mar 2010 Sep 2010 Mar 2011	Progress reports Final report
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.	Types of barrier Types of solutions	Consultation groups Local Networks DC Network	Mar 2010 Sep 2010 Mar 2011	Progress reports Final report
6. Health care services will have received the learning from <i>Dementia Choices</i> to inform the delivery of self-directed support programmes	Email and web based sharing figures Events	Project reference group Web DC Network	Dec 2010 Mar 2011	Final report

OBJECTIVES	OUTPUTS	OUTPUT INDICATORS	INFORMATION COLLECTION METHODS	WHEN	REPORTING METHODS
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.	Information provision	Draft information guides	Consultation groups Local networks	Mar 2010 Sept 2010 Mar 2011	Progress reports Final report
2. Develop and provide information to promote a more flexible approach to self-directed support which encourages professionals to plan and commission services accordingly	Information provision	Draft information guides	Consultation groups Local Networks DC Network Reference group	Mar 2010 Sept 2010 Mar 2011	Progress reports Final report
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	Information provision	Draft information guides	Consultation groups Local Networks DC Network Reference group	Mar 2010 Sept 2010 Mar 2011	Progress reports Final report
4. Nationally disseminate the learning, information and advice from the pilot sites identifying the possible solutions to overcoming these barriers	Information provision	Draft information guides	Consultation groups Local Networks DC Network Reference group	Mar 2010 Sept 2010 Mar 2011	Progress reports Final report

5. Facilitate a <i>Dementia Choices</i> Network for learning, and information exchange	Information provision	Number of network meetings Numbers of members	DC Network meetings	Mar 2010 Sept 2010 Mar 2011	Progress reports Final report
6. Organise and facilitate a <i>Dementia Choices</i> reference group of key stakeholders	Information provision	Numbers of meetings Numbers attending	Reference Group meetings	July 2009 Feb 2010 July 2010 Dec 2010 Mar 2011	Progress reports Final report
7. Support the development of local networks of stakeholders in the pilot sites	Service improvement	Numbers of meetings Numbers attending	Local networks	Oct 2009 Sept 2010 Dec 2010 Mar 2011	Progress reports Final report
8. Hold a national awareness raising event in year one of the project and an end of project event in year two	Information provision Service improvement	Events attended and held	DC Network Reference group Local networks	Mar 2010 Mar 2011	Progress reports Final report

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