The Dementia Choices project was set up by the Mental Health Foundation to explore and promote self-directed support in social care for people living with dementia, their families and friends, and staff who support them. It was a two year project based in England which began in April 2009 and concluded in March 2011.

Self-directed support is a new way for people to regain and remain in control of their lives. Self-directed support, including direct payments and individual budgets, enables people living with dementia (and their carers) to have more freedom and choice about the social care services they receive.

Four pilot sites were involved throughout Dementia Choices to explore and promote what people living with dementia might want from self-directed support and the kind of information they need. Some truly personalised support, and real choice and control, was achieved for individuals. However the project found that there was a very low level of awareness and understanding of self-directed support among people living with dementia and their family carers, and that a wide variety of social care workers at a local level needed practical information about how self-directed support can work for people living with dementia.

To help address these problems the project produced a range of materials for people with dementia, their families and friends and staff working in social care, to raise awareness and provide information about self-directed support.

The uptake of self-directed support by people living with dementia remains low, but Dementia Choices identified some of the barriers that prevent people living with dementia accessing and benefitting from self-directed support and offered potential solutions that may help overcome these barriers.

Background: personalisation and dementia

In 2007, the Government published a concordat, Putting People First, between central government, local government and the social care sector. In this, personalisation was linked to adult social care to ‘create a new, high quality system which is fair, accessible and responsive to the individual needs of those who use services and their carers’ (HM Government, 2007). Included in the concordat were the following objectives - that person centred planning and self-directed support would become mainstream; that personal budgets would be available for everyone eligible for publicly funded social care support; and that direct payments would be utilised by increasing numbers of people.

The implementation of the personalisation changes detailed in Putting People First was seen as key to delivering Objective 6 of the National Dementia Strategy (Department of Health, 2009). This set out the Government’s intention to improve community personal support services by providing an appropriate range of flexible and reliable services to support people with dementia living at home, responsive to the personal needs and preferences of each individual.
More recently, personalisation has been detailed as one of the seven principles of modern social care that the coalition Government has presented in its new vision for social care in England (Department of Health, 2010). Under this vision ‘individuals not institutions take control of their care. Personal budgets, preferably as direct payments, are provided to all eligible people. Information about care and support is available for all local people, regardless of whether or not they fund their own care’ (p8). The vision includes a commitment to ‘extend the greater rollout of personal budgets to give people and their carers more control and purchasing power’ (p6).

Against this policy background, however, evidence suggests that the use and take-up of self-directed support by certain groups, including people living with dementia and people with mental health problems, has remained limited. A recent report published by the Alzheimer’s Society (2011) found that only 14% of questionnaire respondents said that they were using a personal budget or direct payments, with 60% of respondents reporting that they had not been offered a personal budget at all (an earlier survey had suggested that of all those receiving direct payments, only 0.1% had mild to moderate dementia (Davey et al, 2007)). However, problems remain with obtaining accurate information on how many people with dementia actually receive self-directed support. Local authorities do not include diagnoses of dementia in their data concerning the numbers of people in receipt of self-directed support.

Establishing and running Dementia Choices

Dementia Choices began in April 2009 with the overall aim ‘To explore, support and promote different forms of self-directed support (SDS), including direct payments, individual budgets and personal budgets, for people living with dementia and their carers’. The project was funded through the Department of Health’s Innovation, Excellence and Service Development Third Sector Investment Programme.

Organisations from across England were invited to become a pilot site for the project, with four sites being selected to deliver the Dementia Choices work:

- Bury Metropolitan Borough Council
- Cornwall Care Ltd
- Crossroads Care Cambridge City
- London Borough of Redbridge

Each pilot site was offered a training day on personalisation and dementia as well as ongoing service improvement support. The training was subsequently developed and shared as a resource for trainers in the final range of information materials produced by the project.

The pilot sites conducted two rounds of consultations with people living with dementia, their carers and practitioners that looked at the information needs regarding self-directed support for people living with dementia. Information materials produced by Dementia Choices incorporated the views, information and feedback gained from these consultations.

In addition to the work of the pilot sites, the Mental Health Foundation hosted and facilitated a Dementia Choices reference group, whose members included someone living with dementia, family carers, practitioners and representatives from key organisations. The reference group met regularly over the lifetime of the project, and fed back on the various drafts of the information materials. A virtual Dementia Choices Learning and Development Network was also established at the outset of the project and consisted of over 200 individuals representing a wide range of national stakeholders and organisations with an interest in this field.

The final range of Dementia Choices information materials include:

- A postcard for people living with dementia and their families
- A leaflet for people living with dementia and their families
- A practitioner’s guide
- A trainer’s resource
- A short film about individuals’ experiences of self-directed support

These resources can be downloaded from www.mentalhealth.org.uk/dementiachoices
The Dementia Choices findings

The project set itself six outcomes. These are listed below, with a brief assessment of how well the outcomes were achieved during the lifetime of the project.

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.

Truly personalised support is happening, as is real choice and control, but only for some people living with dementia. The pilot sites experienced limited uptake of self-directed support, and indicated that progress had been difficult for a number of reasons, not least the difficulties involved in trying to implement change at a time when the capacity of local authorities to develop and improve their services is under immense pressure.

In spite of the limited uptake of self-directed support, the pilot sites made considerable progress in the provision of information and support for those eligible for self-directed support. They supported people in case review meetings to consider self-directed support as an option and provided information to local service providers.

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.

Considerable progress was made in project sites in raising levels of awareness and expanding knowledge of self-directed support among these groups. The greatest progress was made with local organisations that already had some existing awareness and understanding of self-directed support. The pilot sites found that promoting understanding among people living with dementia and carers often provided the biggest challenge, as typically these groups were less well informed than professionals dealing with dementia.

Case study

Mrs A is an elderly lady who has lived an almost reclusive life with her husband for the last 50 years. Last year her husband died and she is in the later stages of dementia. She is unable to undertake personal care tasks or prepare meals. She has a sister who visited once a week to bath her and had agency care workers (via social services) visiting to make meals every day. Mrs A did not go out of the house or see anyone except her sister and brother-in-law and her agency care workers.

Mrs A’s greatest fear was going into residential care. She wished to remain in her own home where she had lived all her adult life with her husband.

Mrs A took on a personal budget which was managed by her brother-in-law. With the budget she purchased care from a private agency for her personal care needs and to prepare her meals. The care workers were able to come at a time that best suited Mrs A and she had the same care workers every day. Mrs A also purchased extra hours from her care workers with the intention of using these hours for social activity - going out to the shops and attending social activities to help prevent isolation.
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.

Although relatively low numbers of people within Dementia Choices took up self-directed support, satisfaction levels were good for those who did, both in terms of the support arrangements and the outcomes. As one of the pilot sites put it:

“For the people who have got a personal budget, it is working really well and they are living their lives in a way in which they choose. We have low numbers of people choosing self-directed support. However, all these people are satisfied with their support arrangements.”

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.

Several positive individual stories concerning accessing self-directed support have emerged from Dementia Choices and have been shared through case studies included in the Dementia Choices information materials. The short film produced by the project also includes interviews with people living with dementia and carers detailing their experiences of self-directed support. You can watch the film at www.mentalhealth.org.uk/dementiachoices

Perhaps encouragingly, there were no ‘controversial’ or negative stories to emerge from the work, although this may be partly due to the relatively low numbers of people accessing self-directed support at the pilot sites. This is itself a cause for concern and suggests that despite some good work (see 5 below), there is still some way to go to in getting across the potential benefits of self-directed support to people living with dementia and their carers, and overcoming any concerns they have.

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.

The work of local stakeholders across the pilot sites was impressive in attempting to address the barriers to uptake of self-directed support and to find possible solutions. The local training events organised as part of the project provided valuable opportunities for stakeholders to network and to discuss thoughts on personalisation and the provision of self-directed support for people living with dementia. The pilot sites are continuing to work with stakeholders, engaging with professionals to develop work plans that will provide on-going education and information on self-directed support and how people living with dementia and their carers can access it locally.

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

Dementia Choices has worked closely with health care services in the pilot sites and has also shared the learning nationally with health care services through ongoing liaison with the Department of Health’s national personal health budgets programme.

The Mental Health Foundation has produced a range of Dementia Choices products (listed on page 2) which address the need to raise awareness and understanding of how self-directed support can work for people living with dementia, including a guide for practitioners and a resource for trainers. The guide for social and health care practitioners is written in a question and answer style, using questions posed by people living with dementia and providing the corresponding practitioner answers. This should enable practitioners to discuss with confidence the issues around self-directed support that may arise in their work with people living with dementia and their carers. The trainers’ resource provides a half day training module aimed at staff who work with people with dementia.
Conclusions

The Dementia Choices project achieved its ambition to explore, support and promote self-directed support for people living with dementia in the pilot sites involved in the project. However the project also revealed that there still remains much to do in enabling greater numbers of people living with dementia to access and benefit from self-directed support. While we do not want to see people who are currently satisfied with their existing service support forced into taking up self-directed support options, we do want everyone to have the opportunity to consider those options so that they can make an informed choice.

A positive that can be taken from the work is that truly personalised support and real choice and control were achieved for a number of people living with dementia at the pilot sites, and that the issue of self-directed support for people living with dementia and their carers achieved a higher profile as a result of the work. Where people living with dementia chose to take up self-directed support the satisfaction levels have been good.

There are concerns about the low level of awareness and understanding of self-directed support among people living with dementia and their family carers, which is clearly a major factor behind low take-up. It is also clear that local social care workers could benefit from practical information about how self-directed support can work for people living with dementia. The information materials produced by Dementia Choices go some way to address this need and allow the learning gathered by Dementia Choices to be widely shared.

Key learning

Barriers

Dementia Choices identified some of the barriers to people living with dementia accessing and benefiting from self-directed support through the consultations held at the four pilot sites. These included:

- the ‘substantial and critical needs’ eligibility criteria for publicly funded social care being used by some social services staff as a reason why self-directed support wouldn’t be possible for people living with dementia (because only people with more severe dementia met the criteria); some staff were also uneasy about people with dementia holding their own budget and finding their own support
- Misinformation about self-directed support from poorly informed staff or organisations, with some organisations suggesting that self-directed support would not be possible for someone living with dementia
- Safeguarding concerns in respect of possible abuse by people managing personal budgets on behalf of people living with dementia who lack mental capacity or by people from services providing care and support
- Lack of awareness about self-directed support among people living with dementia and their carers, and lack of understanding about the details of self-directed support, with many people feeling they did not understand how self-directed support could work for them
- The perception, particularly from carers, that taking on self-directed support would be an added responsibility that could become unmanageable
- Service providers’ apprehension about their own service viability in a changing market and a challenging economic climate, and the fear of some organisations that they would lose services
- Some people’s satisfaction with the care they were currently receiving meant they could not understand why they might want self-directed support when they were happy with their current service and how it was provided (arguably a perfectly reasonable position).
Solutions
Potential solutions to overcome these barriers may include:

• Awareness raising campaigns and face to face discussions with people living with dementia and their carers about the benefits of self-directed support - this could include local information sessions or roadshows that create a positive feel about self-directed support

• Balanced, user-friendly information that tackles people’s concerns about self-directed support and sets out potential benefits - information needs to be jargon-free and targeted towards people living with dementia and their carers in a way that best suits their needs

• Better promotion of self-directed support to people with dementia and their carers by GPs, as this is often where first contact is made with the majority of people who need support – greater GP involvement was frequently mentioned as a potential solution given the central role of GPs in recognising dementia and signposting the support options

• The provision of adequate support and guidance to those living with dementia and their carers at each stage of the self-directed support process

• The creation of local groups of people living with dementia who are currently using self-directed support and their carers, to be ‘champions’ who can give an account of self-directed support to others.

Recommendations
We recommend that all these potential solutions are adopted by local health and social care providers, and built into their guidance and protocols on personalisation and on dementia care.

In addition, at a national level, we recommend that the emerging evidence of the benefits of self-directed support for people living with dementia and their carers is made available widely through the Department of Health, professional health and social care bodies, local authorities and national voluntary sector organisations.

We would also recommend that the Care Quality Commission (CQC) closely monitors local authorities’ provision of self-directed support and personal budgets to ensure that all groups benefit equally from personalised support, particularly those groups such as people living with dementia who are not accessing self-directed support to the same extent as other care groups, and that safeguarding arrangements are effective.

Finally, we recommend that following diagnosis and while the person still has capacity, the person with dementia is provided with information about how to plan in advance for a future loss of mental capacity. This might include opportunities (such as when making a Lasting Power of Attorney) to identify what type of care and support they would like to receive, who might provide it, and who might manage their personal budget on their behalf.
Glossary

**Dementia**
is the generic term for a range of conditions affecting around 800,000 people in the UK. Common symptoms include a progressive decline in mental ability which affects memory, thinking, problem-solving, concentration and perception. Dementia occurs as a result of the death of brain cells or damage in parts of the brain that deal with our thought processes, and is almost invariably a disease of ageing.

**Personalisation**
is the term given to a policy of recent Governments to make public services more responsive to individuals' preferences and needs. The Social Care Institute for Excellence (SCIE) states that personalisation "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.... [it] is about giving people much more choice and control over their lives".

**Self-directed support**
refers to the variety of different approaches to delivering personalised care by allowing an individual to control the resources for, and make choices about, the support that they receive. Self-directed support should be available to anyone who is eligible for social care provision from social services, and may be funded through personal budgets, including direct payments.

**Personal budgets**
are allocations of social care funding to individuals with an assessed ongoing need for social care that is publicly funded (i.e. by a local authority social services department). They can be offered as a direct payment or held as an account managed by the local authority or another person – or can be a mix of both.

**Direct payments**
are cash payments that are made in place of direct service provision by social care services that the individual has been assessed as needing by their local authority social services. They allow the individual, or someone appointed by the individual, to arrange and pay for their own services to meet their needs. Since 2009 people who lack mental capacity to consent to receiving or managing direct payments have been able to receive them through a carer or ‘suitable person’ who can act on their behalf.

References


www.pssru.ac.uk/pdf/dprla.pdf


www.dh.gov.uk/en/Aboutus/Features/DH_121664

HM Government (2007) ‘Putting People First: A shared vision and commitment to the transformation of social care’
The Mental Health Foundation is a UK-wide charity that carries out research, campaigns for better mental health services, and works to raise awareness of all mental health issues to help us all lead mentally healthier lives.