



Personalisation and growing old well with dementia

Personalisation is described as the dominant idea in social care and social work today, and there is political consensus that a personalised approach should be taken for all growing old with dementia.

Dementia is a huge problem and deeply feared with less than half of those living with the condition having a formal diagnosis. There are real issues about the continuing availability of residential care, and potentially a colossal financial burden for individuals and the state.

This paper looks at what is meant by personalisation and then at its origins and some of the tensions and shortcomings concerning personalisation – aggravated as they are by financial stringency. There are two short sections on carers and self-funders, followed by a section on specific issues concerning growing old with dementia. The paper concludes with a summary of the writer's thoughts, focusing particularly on the community context, and a 10 point strategy for going forward.

Written by **John Colquhoun**, retired solicitor post-graduate student in 'Disability Studies: Inclusive Theory and Research' at the University of Bristol for the Housing Learning and Improvement Network

SELF CARE WEEK
14-20 November 2016



November 2016

Introduction

Some of us associate personalisation with direct payments made direct to disabled people to pay for their support; historically speaking this is correct, but person-centred care, and personalisation and personal budgets were conceived 15 to 20 years later. Whilst direct payments may not be appropriate for the many who are growing old with dementia, the political consensus is that a personalised approach should be followed, using all available resources, to allow people with dementia to grow old *well* with their condition. In this paper for the Housing LIN, I argue that for people growing old with dementia it is the person-centred approach, with a thorough Care Act assessment, rather than a personal budget, that should be the yardstick. However these will count for little without a supportive and safe environment.

There were expected to be 850,000 people with dementia in the UK in 2015, increasing to over 1 million by 2025 and to 2 million by 2051. It is hoped that this may be a worst-case scenario since the anticipated prevalence of dementia and cognitive impairment in some western countries has reduced, possibly on account of changes in lifestyle and the reduction in cardiovascular risk factors (Smith and Yaffe, 2013).

In 2013, only 48% of people with dementia in England were estimated to have a formal diagnosis or to have contact with specialist services (DH, 2013). However the Alzheimer's Society states that "dementia is the most feared health condition in the UK, perhaps explaining also why almost two-thirds of people surveyed (62%) felt a diagnosis would mean their life was over" (2016).

Quite apart from the social cost, there is general concern that, due to changing demographics of our population, the future financial burden of dementia, both for our society as a whole and for the individuals who have the means to pay for their own care, will increase significantly. Macdonald and Cooper (2007) highlighted serious issues concerning care home places for people with dementia, concluding that there is an impending crisis of availability. What is certain is that there will be an increasing need for provision of care and support for people growing old with dementia, so that they may live as long as possible in their own homes.

Personalisation has come to be accepted by successive governments of varying hues, and is described by Beresford as being "without question the dominating idea and development currently in social work and social care" (Beresford, 2014 p. 1). However, it is considered not to have lived up to the rhetoric surrounding its introduction.

Understanding personalisation

Much has been written about what personalisation means. Sarah Carr writes: "Personalisation means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support." She then goes on to define personalisation in rather more mechanistic terms providing quite a comprehensive shopping list of examples of good practice, but one that is light on values (Carr, 2012 p. 2).

Beresford (2014) reports on the more value- and relationship-based opinions that emerged from, 'The Standards We Expect' project, whose purpose was to find out what people at the front line of social care – service users, carers, face-to-face practitioners and managers – saw personalisation or person-centred support as meaning. It was not associated narrowly with personal budgets, and could be "seen as a reaction against long-standing, paternalistic and institutionalising approaches to support and social care". The key components cited were:

- putting the person at the centre, rather than fitting them into services;
- treating service users as individuals;
- ensuring choice and control for service users;
- setting goals with them for support;
- emphasising the importance of the relationship between service users and practitioners;
- listening to service users and acting on what they say;
- providing up-to-date, accessible information about the appropriate services;
- flexibility; and
- a positive approach which highlights what service users might be able to do, not what they cannot do. (Beresford, 2014 p. 21)

New Labour's, *Putting People First* (2007), set out the values intended to underpin personalisation:

"The time has now come to build on best practice and replace paternalistic, reactive care of variable quality with a mainstream system focused on prevention, early intervention, enablement, and high quality personally tailored services. In the future, we want people to have maximum choice, control and power over the support services they receive....."

"The state and statutory agencies will have a different not lesser role – more active and enabling, less controlling." (p. 2)

The language of the Coalition Government's vision for personalisation, set out in, 'A Vision for Adult Social Care: Capable Communities and Active Citizens' (DH, 2010), is not dissimilar. Both refer to the use of personal budgets. The latter report says:

"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." (DH, 2010 p. 15)

The foreword to 'A Vision for Adult Social Care' concluded with a call for "different organisations and communities [to come] together to develop new ways of caring for people" (DH, 2010 p. 5) quoting from Lord Seebohm's report that "social care should enable the greatest possible number of individuals to act reciprocally giving and receiving service for the well-being of the whole community" (Seebohm, 1968). This is clearly linked to the thinking behind David Cameron's, 'Big Society' (2010). Following what he refers to as Émile Durkheim's, 'socialist theory', Dawson warns that "the likely result of [the Big Society] would be a 'postcode lottery' whereby affluent areas are more effective in fulfilling their sectional desires, derived from egoistic individualism, than their less affluent counterparts" (Dawson, 2013 p. 87).

The suitability of an individual's accommodation is specifically one of the matters relevant to their wellbeing required to be promoted under the 2014 Care Act. However the emphasis on the provision of services and support in the descriptions of personalisation underrates the importance of housing and the local environment on people's lives. (After all an occupier of a unit of accommodation is usually not a 'service-user' in relation to that *occupation*, even though he or she may receive health or support services by reason of that occupation.)

SCIE say:

“Housing and the local environment make a critical difference to people’s ability to live independently. Safe, settled housing and a place in the community underpin positive mental and physical health. The challenge is to offer people a choice in how and where they live and to ensure that homes are well designed so that people can stay independent for as long as possible.” (SCIE, 2012)

Similarly, in their report for The Kings Fund and Nuffield Trust Humphries et al say that there is “good evidence about the importance of housing in reducing the need for health and social care services and offering care options that achieve better outcomes at lower cost” (2016).

Origins of personalisation

Personalisation has evolved from two contrasting sources. One was the struggle of the disability movement to secure support services to enable disabled people to live independently. Disabled people set up the first Centres for Independent Living in the UK in Derbyshire and Hampshire in 1984; following active campaigning, in 1984 the Department of Social Security set up the – now controversially discontinued – Independent Living Fund, under which the Department made cash payments direct to individuals. In spite of questionable legality, around this time, Hampshire County Council started to make payments direct to individuals for their care, but it was not until a decade later that direct payments were fully legitimized following the passing of the Direct Payments Act in 1996.

Beresford writes that from the start the early direct payments were rooted in a set of clear yardsticks, that the “service user would be in control of their support”, that the money provided would match their needs “to secure their equal human and civil rights” and that they would have “the support they needed to be able to manage a direct payments system – to be provided through the development of local user-led organisations” (Beresford, 2014 p. 17).

A more immediate influence on the personalisation agenda was the White Paper, ‘Valuing People’ (DH, 2001), which set out to transform the way that people with learning disability were supported in England, with its ‘Key Principles: Rights, Independence, Choice, and Inclusion’ and its ‘person-centered’ approach to planning and delivering services.

Even though direct payments had been introduced in 1996, their uptake by those with learning disabilities was very slow, on account of concerns (until the law was amended in 2009) about possible lack of capacity to consent to receiving them. The implementation was piloted by In Control, a voluntary organisation, which was not user led, and the Care Services Improvement Partnership, which was a government organization (Boxall et al., 2009). Boxall comments that, although personalisation was developed particularly in relation to people with learning difficulties, they had been largely excluded from discussion about its development. It was in essence a top-down policy, and a product of the paternalistic ‘normalisation’ thinking developed by non-disabled academics and professionals in North America – at the other end of the spectrum from the disability movement and the social model of disability (which holds that disabled people are not disabled because of their impairment, but by the structures or barriers present in society).

Shortcomings and tensions

A common theme of the failure of the policy to live up to its promise is the lack of funding for implementing the policy. This is undoubtedly a major contributory factor.

It is widely acknowledged that, for the policy to work, a change in culture and learning to do things very differently are required for those planning and delivering services; there must be greater understanding of people in the context of their communities, and of the strengths and assets of each.

There are widely held views that personalisation is a neo-liberal and right wing idea based upon consumerist rather than rights based principles. It is correct that consumerism and choice are closely linked, but wrong to denigrate personalisation simply because it involves individuals in exercising choice (which is just what the early activists were seeking to do). I believe that Duffy correctly identifies two ideas in particular that are missing from the simplified left–right battle:

- citizenship – that we should live, in all our diversity, as free and equal citizens; and
- community – that we should live together with a shared commitment to the world. (Duffy, 2014 p. 167)

The acceptance of the ‘social model of disability’ in the mainstream thinking of our health and social care services, suggests that the argument has moved beyond society’s oppression, to a more nuanced thinking about social justice being available to all and facing up to the unintended consequences of what appear to be sound emancipatory social policies. There is little difference between the outcome of choice to live independently fought for by the independent living movement and the ability of disabled people today to have a real say, through person-centred care, in the ‘what, when and where’ of services or facilities that they wish to enjoy in order to improve or make possible their lives as part of the community. In regard to people growing old with dementia the main difference perhaps lies in their being much less able, to make good choices without assistance, or to advocate for themselves than the early independent living activists.

I have referred to unintended consequences of social policies. Personalisation, and in particular personal budgets and direct payments, have their share of these, particularly in relation to older people with dementia. Who decides, when the individual’s capacity to make decisions is impaired? There are provisions in the Mental Capacity Act 2005 for another to do so, and this is most straightforward where a welfare power of attorney has been registered, and their wishes are understood. What should be the role of the social worker in the course of assessment and support planning? Will the risk averseness of the social worker stand in the way of the service user’s own wishes and aspirations being fulfilled? By way of example Ellis writes that:

“striking the balance between risk enablement and safeguarding is challenging where time for documenting decision making is limited, let alone reflection and relationship building. Social workers’ capacity to work in risk-enabling ways is further compromised by fear of blame or liability, or confusion about balancing safeguarding duties”. (Ellis, 2014 p. 2282)

Housing is an area where risk and safeguarding issues are especially pertinent, particularly as:

“85 per cent of people would want to stay living at home for as long as possible if diagnosed with dementia. Yet a third of the general public wouldn’t know where to find information about how to make their home suitable.” (YouGov poll commissioned by Alzheimer’s Society, 2014)

One of the consequences of people's freedom to choose personal assistants is the much greater scope for less skilled, poorly trained, badly paid support workers, and lack of professional oversight, quality control or public accountability. The budget allowed may not allow any real choice. Whilst being able to choose who will provide the care is, for many, essential where intimate personal care is concerned, it is equally important that choices are made in the light of adequate information. Those with the most social capital will invariably make better choices than those with less social capital, whose needs by implication will be greater.

Spandler (2004 p. 203) sets out very clearly the ideological conflict between what she describes as two "seemingly conflicting, yet equally progressive, challenges for social policy" – namely the ideologies of individual choice and collective provision. She illustrates the two positions with the work of (Stainton, 2002) and (O'Brien, 2001). She says that Stainton argues that the "challenge for social policy is not to find better services, but to create a structure in which individuals can articulate their claims for the support they need to equalise their basic capacity to formulate and pursue self-determined plans and purposes" (2002 p. 756) and that, alternatively, O'Brien emphasises the necessity of providing the "best conditions which will evolve and develop services that offer highly customized, specialized, publicly accountable, collective service provision and assistance" (2001 p. 2). I do not consider that the ideologies of individual choice and collective provision need to be mutually exclusive; there is, however, clearly a limitation in personal choices for older people with dementia, when a previously block-funded specialist dementia day centre has to close on account of lack of funding, because of not enough people exercising their consumer choice to go there, or even because local authorities have narrowly interpreted personalisation and personal budgets as not requiring access to community or group activities.

Lloyd (2014) is concerned about the capacity of older service users to engage in the personalisation agenda, commenting that "both preventive and personalisation agendas portray an image of an engaged and active consumer citizen who is in charge of their own destiny and able to manage their own care". She refers to this as a form of abandonment of collective responsibility.

Lloyd makes a complementary point, about our social nature, when she writes of feminist ethicists' arguments that we should "all be understood as individuals with rights and responsibilities but that our individual identities are the *outcome of* our social nature, not *prior to* it" and says that "our social nature reinforces the point that dependency on others is a normal aspect of life, as is our need to give care and support to others". She refers to Kittay's (2002) concept of 'nested dependencies' to "describe the way that individuals who require support and care are helped by others who, in turn, benefit from support and care"; Lloyd also suggests that this "perspective on networks of care and support might be seen as consistent with some versions of personalisation in which individuals are assisted to find ways of meeting their needs that recognise their relationships with others" (Lloyd, 2014 pp 60-1). I refer below to common themes of good quality support and care for people with dementia. However, to achieve stimulating and meaningful engagement, it is essential that the family and community networks of care and support of the person with dementia are *built upon* rather than *removed* by any individual package of care arranged for that person (for instance, by an unnecessary and expensive admission to a care home).

The carer's perspective.

The family carers are very often the primary network of support for older people living with dementia. The Care Act 2014 stipulates that they are entitled to a carer's assessment, before the service user's assessment. The service user's assessment should reflect only the care and support that the carer *wishes* and is sustainably able to give. However, even though carers obtained the right to an assessment in 1995, Mitchell et al. write about the low frequency of separate carer assessments reported in the Carers and Personalisation study (2011-13) and "that there was an absence of evidence of carers having their own support plan that included employment, training or leisure activities. Carers had low expectations of receiving such support" (Mitchell et al., 2014 p. 73). They found that "routine practice generally did not:

- link information from service user and carer assessments;
- ensure that information from separate carer assessments contributed to service user support planning;
- ensure separate carer assessments were conducted before service user PB [personal budget] levels were adjusted to take account of help from carers"

considering that these were "structural design problems within a system of personalisation that fails to adequately recognise the rights of carers". (p. 73)

It is disappointing that a recent assessment by Carer's Trust recorded that

"69% of carers responding to our survey noticed no difference since its introduction and many expressed frustration and anger at the lack of support they received in their caring role".

It is good that independent carers' organisations are sometimes contracted to carry out carers' assessments, but is there a conflict of interest when they depend on a contract with the local authority for this work?

Self-funders

There are no reliable statistics on proportions of those paying for their own social care. Henwood (2014) writes that it is estimated by IPC that 45% of residential home and 48% of nursing home places together with 20% of home care are privately funded (IPC, 2011), but says that these estimates are likely to be incomplete, particularly in relation to home care. IPC estimated that the care home market for self-funded residential care was £4.9 billion (with a further 168,000 care home places being 'topped up' by individuals' private funds) and for the home care market was £652 million; they say, too, that the number of self-funders is predicted to rise due to factors, including population ageing and rising eligibility thresholds' (IPC, 2015). They report that the fourth Care Act implementation stocktake (published in August 2015) indicated that '*uncertainty about additional demand from self-funders*' was the number one risk identified by local authorities in delivering the Care Act reforms (IPC, 2015). There are significant long term cost implications, that need to be addressed, since LGIU calculates that on average 24% of self-funders fall back on state support; they point out that this was at a cost in 2011-12 of £425m which is more than four times the savings that adult service departments were to make in 2013-14 (Carr-West, 2013).

Referring to her previous research findings for the Putting People first Consortium (Henwood, 2010) Henwood says that:

“Major life-changing decisions were often made in crisis situations and on the basis of no information or advice on navigating the complex world of care and support. Far from exercising choice and control many people have experienced a profound sense of powerlessness and uncertainty, and lack of meaningful choices.” (Henwood, 2014 p. 76-7)

She traces the increasing requirements on local councils to assess the needs of those who might need social care services introduced between 1998 and the passing of the Care Act in 2014, when substantial changes were made requiring local authorities to “establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support carers”.

However, it is questionable how many local authorities are successfully communicating the information and guidance that people seeking care and support are entitled to, although it is clear that there are some examples of very good practice. Perhaps not surprisingly IPC, citing Henwood (2010), report that a qualitative investigation carried out, retrospectively tracking the journeys by people paying for their own care, found that almost nobody identified social services as a source of information or advice, and that those who did, often had a negative experience that focused solely on their financial status, rather than needs for care and support (IPC, 2015 p. 27). Having regard to the community-based signposting work done in local communities by Village and Community Agents in some counties, it is likely that there may be pockets of better practice in the counties where they operate. Better practice will need to be the norm, if local authorities are to be able to implement the recommendations of the Dilnot Commission (when the Care Act 2014 cap on expenditure payable by self-funders is scheduled to come into force in 2020). Local authorities will need to have an influential and proactive role in facilitating the development of their local provider markets to better meet the needs of all.

Particular issues of people growing old with dementia

In her report for the Mental Health Foundation, Goodchild (2011 p. 7) writes that there is no reliable data on the number of people with dementia who are in receipt of or have been assessed for personal budgets, but says that we know anecdotally that people with dementia are not accessing personal budgets to the same degree as other care groups. Goodchild says that interviews showed that where a *direct payment* was made to a person with dementia there was almost always a carer who managed the money, thereby indicating that most local authorities had yet to develop money management services for people with dementia.

Orellana (2010) in her report for Age UK reports that many older people found managing their budgets burdensome rather than empowering, and also that older people are likely to be allocated smaller personal budgets than younger people with comparable levels of need, saying that this reflected widespread age discrimination in the social care system, both in terms of the breadth of needs assessment and of resource allocation (p.15).

It is generally accepted that working with older people living with dementia has many challenges. Goodchild says the complexities may include denial and lack of insight, levels of need fluctuating on a day to day basis, and the fact that dementia is a degenerative condition.

People with dementia may experience difficulties of comprehension and inability to articulate their own needs. In a period of insight they may be able to come up with a solution that feels good for them, and if unable to express themselves in straightforward language are “likely to express themselves in verbal and non-verbal behaviour, which an assessor should have the skills to interpret” (Goodchild, 2011 p. 6).

Goodchild comments that there are some common themes about good quality support and care for people with dementia, which include:

- familiar surroundings, continuity of care worker (both from the point of view that they are familiar to the person with dementia, and from the fact that the worker will have a good understanding of that person)
- Routine can be vital
- Stimulating and meaningful engagement and activity that is manageable by the person with dementia.

She says: “For these very reasons, individualised, tailored support and care that a personal budget can facilitate can have enormous benefits to a person with dementia.” She refers also to “numerous personal stories in the current literature and websites that are testimony to the improved outcomes that personal budgets can bring” (Goodchild, 2011 p. 6).

However, she writes that a number of local authority interviewees “reported that keeping a cap on the social care budget presented a major concern in introducing personal budgets for people with dementia” and that another “authority that had yet to introduce personal budgets for people with dementia went as far as to admit that with the tightening budgets that local authorities are facing that people with dementia might have ‘missed the boat’ with regard to personal budgets”. The additional costs of brokerage and managing the money was of great concern to a number of local authorities (Goodchild, 2011 p. 11). There has been no let up in cuts to local authority funding, as reported on 4th June 2015 in the Guardian (Butler, 2015).

The bleakness with regard to funding is reiterated in the report published by The Kings Fund and Nuffield Trust, which says that the “possibility of large-scale providers failures is no longer [a].. question of ‘if’ but ‘when’ and such a failure would jeopardise continuity of the care on which older people depend” (Humphries et al., 2016).

Inevitably comorbidity is more common for those with dementia, and it is in the transfer between services that a personalised approach is vital so that the additional challenges on account of dementia can be managed. The Chairwoman of Camden Clinical Commissioning Group writes:

“The care of those with complex needs is often poorly co-ordinated, fragmented and reactive, rather than planned. This frequently results in admission to hospital, and those with complex needs often have worse outcomes, longer stays (1.5 times as long) and loss of independence.” (Sayer, 2016)

The role of housing providers in enabling people with dementia to continue to live in their homes should not be underestimated. In the early stages of a person’s illness, before it has been diagnosed, an adequately trained housing worker is well placed to notice that there may be an issue, and to facilitate early intervention. Later on, the housing provider has an important role in ensuring that the person with dementia will have access to the support services that individual needs and wishes to have.

There is no doubt that telecare and assistive technology (AT) will play an increasing part in enabling a person with dementia to continue to live safely in their homes, and to engage in activities they choose, both inside and outside the home. However there is “limited research identifying what types of AT are in use, how they are being used, or what are the perceived gaps in support” (Boger et al., 2014).

Ward and others comment that electronic assisted living technologies (eALT) products and services are currently provided predominantly through the NHS and local authority social services departments, with many people not being eligible for such services on account of factors such as means testing and the strict applicability of eligibility criteria. As a result people were looking to the self-funded consumer market to meet their needs, although this market was not well developed in the UK. It seems clear that health and social care providers must develop a knowledge base concerning the eALT that is available, affordable and effective, so as to be able to comply with their obligations under the Care Act 2014 to give advice and information about what can be done to prevent or delay the development of further needs in the future (Ward et al., 2016).

I have referred above to the local environment making a critical difference to people’s ability to live independently. Davis and others provide a definition of a dementia friendly environment as one that:

“can be defined as a cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way”. (Davis et al., 2009 p. 187)

Although this was written in the context of residential care, it is no less pertinent for people living in their own homes in the community. The growing numbers of ‘dementia friendly communities’ (now 211 in England and Wales), promoted by Alzheimer’s Society and Public Health England, and recognised in accordance with PAS 1365:2015 (PAS, 2015), have significantly exceeded the original target, and are supplemented by over 1.7 million people trained to be ‘dementia friends’. Research has recently been commissioned by the Department of Health (DH, 2016) to develop a “solid national evidence base promoting the benefits of becoming dementia friendly”. The research is to give particular consideration to what constitutes a dementia friendly community, and to what people with dementia need and would like from dementia friendly communities to help them to continue to live independent and fulfilling lives for as long as possible; it should help to determine how communities can become more dementia friendly and explore the social and potential economic benefits from a community becoming dementia friendly.

Concluding thoughts and strategy for going forward

The tensions that I have mentioned coalesce in a very particular way in regard to individuals living with dementia. How are people with progressively impaired capacity to be enabled to make good choices, about where they live and the support they receive in a timely manner, and to retain the maximum control over their lives?

Knowledge of what is available and advice on choices both as to housing, and in particular extra care housing, must be accessible to people with dementia; they have a right to receive a publicly accountable quality of, and a risk enabled, service chosen by them (or their proxy), in so far as they are able to choose, and, to the extent that they are not, one that is in their

best interests. Particularly with the shortage of funding, but in any event, such choices must take account of the community context for that person, and having regard to Lloyd's comment that we should "all be understood as individuals with rights and responsibilities but that our individual identities are the *outcome of* our social nature, not *prior to it*" and that "our social nature reinforces the point that dependency on others is a normal aspect of life, as is our need to give care and support to others" (2014 p. 60).

A strategy for going forward

1. Culture Change

Training for values of all involved in delivering assessments, care planning and services to be aligned with the values of person-centred planning.

2. The Universal Offer

The success of the local council in implementing personalisation for people with dementia should be judged by the numbers estimated to have dementia, who have received a Care Act assessment, rather than by the proportion with personal budgets (which will exclude self-funders).

3. Housing

The continuing and future suitability of housing must be central to all individual planning.

4. Carers

The role of carers must be sustainable, so that a robust Care Act assessment should be offered to the carer, taking account of their wishes and aspirations. This should be offered with someone other than the person who assessed the service user's needs, and harmonised with the main assessment (which may need revisiting).

5. Quality of assessment and support

Advocacy or a brokerage service must be offered in relation to services and housing advice, especially where there is no family carer involved. Assessments must include a detailed history including interests, and be carried out by someone with a good understanding of dementia issues, community facilities and the individual's community connections. There must be reliable signposting to others offering advice, including on financial planning.

6. Community capacity

The local authority should promote and encourage 'dementia friendly communities' and tap into and build the capacity of local community organisations and groups that can offer social activities to those with dementia. Examples of activities include: playing golf, singing, knitting, gardening, walking, clubs, baking, or socialising with other like-minded people.

7. Joined up services

Close co-ordination with the NHS and housing providers should be established and maintained, and available NHS funding obtained (including through social prescribing and personal health budgets). There must be good liaison with these services so that transfers between hospital and home or care home are achieved without impacting negatively on the service user.

8. Development of local provider market

The local authority must seek to play an influential role in facilitating the development of its local provider market to better meet the needs of all.

9. Communication

The local authority should revisit its communications strategy with this group, in order to reverse the pessimistic attitudes to dementia that prevail, and to emphasise the (non-means tested) Universal Offer, publicising the good stories arising from people learning their diagnosis and living well with dementia.

10. Data

Record reliable and accessible data, inter alia to support the planning and provision of services, to monitor quality to make service providers accountable, and to research, measure and log effectiveness of services, assistive technology products (and their suppliers) and community assets.

References

2010. London: Cabinet Office.

ALZHEIMER'S SOCIETY. 2016. Alzheimer's Society. Accessed 16th May 2016. Available at: https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2606

BERESFORD, P. 2014. Personalisation: from solution to problem? *In*: BERESFORD, P. (ed.) *Personalisation*. Bristol and Chicago: Policy Press.

BOGER, J., QURASHI, M., TURCOTTE, N. & DUNAL, L. 2014. The identification of assistive technologies being used to support the daily occupations of community-dwelling older adults with dementia: a cross-sectional pilot study. *Disability and Rehabilitation: Assistive Technology*, 9, 17-30.

BOXALL, K., DOWSON, S. & BERESFORD, P. 2009. Selling individual budgets, choice and control: local and global influences on UK social care policy for people with learning difficulties. *Policy & politics*, 37, 499-515.

BUTLER, P. 2015. £1bn further cuts to social care will hit tens of thousands, say experts [Online]. London: The Guardian. Accessed 16th May 2016. Available at: www.theguardian.com/society/2015/jun/04/1bn-further-cuts-to-social-care-will-hit-tens-of-thousands-say-experts

CARR, S. 2012. Personalisation: a rough guide (revised edition). London: Social Care Institute for Excellence.

CARR-WEST, J. T., L 2013. Independent Ageing 2013. Council support for care self-funders. London: LGIU.

DAVIS, S., BYERS, S., NAY, R. & KOCH, S. 2009. Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, 8, 185-203.

DAWSON, M. 2013. Against the Big Society: a Durkheimian socialist critique. *Critical Social Policy*, 33, 78-96.

DH 2001. Valuing People: A new strategy for learning disability for the 21st century London: Department of Health.

DH 2007. Putting People First: A shared vision and commitment to the transformation of adult social care. London: Department of Health.

DH 2010. A vision for adult social care: capable communities and active citizens. London: Department of Health.

DH 2013. Dementia: A state of the nation report on dementia care and support in England. London: Department of Health.

DH 2016. Invitation to Tender: Creating Dementia Friendly Communities – A Policy Evaluation. London: Department of Health Policy Research Programme.

- DUFFY, S. 2014. After personalisation. *In: NEEDHAM, C. & GLASBY, J. (eds.) Debates in personalisation*. Bristol and Chicago: Policy Press.
- ELLIS, K. 2014. Professional discretion and adult social work: Exploring its nature and scope on the front line of personalisation. *British Journal of Social Work*, 44, 2272-2289.
- GOODCHILD, C. 2011. Personal budgets for people with dementia. London: Mental Health Foundation.
- HENWOOD, M. 2010. Journeys without maps: the decisions and destinations of people who self fund – a qualitative study. Melanie Henwood Associates.
- HENWOOD, M. 2014. Self-funders: the road from perdition? *In: NEEDHAM, C. & GLASBY, J. (eds.) Debates in Personalisation*. Bristol and Chicago: Policy Press.
- HUMPHRIES, R., THORLBY, R., HOLDER, H., HALL, P. & CHARLES, A. 2016. Social care for older people. London: The Kings Fund, Nuffield Trust.
- IPC 2011. People who pay for care: quantitative and qualitative analysis of self-funders in the social care market. London: Putting People First Consortium.
- IPC 2015. Understanding the self-funding market in social care. 2nd ed. Oxford: Oxford Brookes University.
- KITTAY, E. F. 2002. When caring is just and justice is caring: caring and mental retardation. *In: KITTAY, E. F. & FEDER, E. K. (eds.) The subject of care: Feminist perspectives on dependency*. Lanham, MD: Rowman and Littlefield.
- LLOYD, L. 2014. Can personalisation work for older people? *In: NEEDHAM, C. & GLASBY, J. (eds.) Debates in Personalisation*. Bristol and Chicago: Policy Press.
- MACDONALD, A. & COOPER, B. 2007. Long-term care and dementia services: an impending crisis. *Age and Ageing*, 36, 16-22.
- MITCHELL, W., BROOKS, J. & GLENDINNING, C. 2014. Personalisation: where do carers fit? *In: NEEDHAM, C. & GLASBY, J. (eds.) Debates in personalisation*. Bristol and Chicago: Policy Press.
- O'BRIEN, J. 2001. Paying Customers Are Not Enough: The Dynamics of Individualized Funding.
- ORELLANA, K. 2010. Personalisation in practice: lessons from experience. Making personal budgets, support planning and brokerage work for older people in later life. London: Age UK.
- PAS 2015. Code of practice for the recognition of dementia-friendly communities. London: BSI Standards Limited 2015.
- SAYER, D. C. 2016. Letter to the Times 3rd October 2016. London: The Times.
- SCIE 2012. Personalisation briefing – Implications for housing providers. London: Social Care Institute for Excellence.

SEEBOHM, F. 1968. *Report of the committee on local authority and allied personal social services*, HM Stationery Office.

SMITH, A. & YAFFE, K. 2013. Dementia (including Alzheimer's Disease) can be Prevented: Statement Supported by International Experts. *Journal of Alzheimer's disease: JAD*, 38, 699-703.

SPANDLER, H. 2004. Friend or foe? Towards a critical assessment of direct payments. *Critical Social Policy*, 24, 187-209.

STANTON, T. 2002. Taking rights structurally: Disability, rights and social worker responses to direct payments. *British Journal of Social Work*, 32, 751-763.

WARD, G., FIELDEN, S., MUIR, H., HOLLIDAY, N. & URWIN, G. 2016. Developing the assistive technology consumer market for people aged fifty to seventy.

Note

The views expressed in this paper are those of the author, and not necessarily those of the Housing Learning and Improvement Network.

About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading 'knowledge hub' on specialist housing, our online and regional networked activities:

- connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- provide intelligence on latest funding, research, policy and practice developments, and
- raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population

For information about the Housing LIN's comprehensive list of online resources on housing and dementia, visit:

www.housinglin.org.uk/Topics/browse/HousingandDementia/

Published by

Housing Learning & Improvement Network
c/o EAC, 3rd Floor,
89 Albert Embankment
London SE1 7TP

Tel: 020 7820 8077

Email: info@housinglin.org.uk

Web: www.housinglin.org.uk

Twitter: @HousingLIN & @HousingLINews