

The key policy and best practice context for the Office for Disability Issues South East Regional Initiative

Centre for Policy on Ageing
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Aims and Objectives

The purpose of this review is to provide an overview of the social and political context of the Office for Disability Issues South East Regional Initiative (ODI-SERI). It looks both at the developing legislative and governmental framework within which the initiative took place and the developing thinking as outlined in reviews, reports and guidance published during the period of the initiative.

The South East Regional Initiative works with older people with high support needs. Whilst we have not sought to describe the profile of this group, we would, however, emphasise two basic points. Firstly the growing diversity within the group and secondly that the number of people with high support needs within the 'oldest old' is set to increase.

Introduction and background

The Office for Disability Issues South East Regional Initiative ran from October 2008 until December 2010.

During that time there have been significant changes in the social, political and professional background against which the individual initiatives have been taking place.

The Office for Disability Issues South East Regional Initiative (ODI-SERI), which examined best ways of designing and providing support to improve the lives of older people with high support needs as a result of increased choice and control. The initiatives comprised two key elements: qualitative research and change management support within and across Oxfordshire, Portsmouth and West Sussex. Two target populations of older people were the main focus of this work: older people currently living in care homes; and older people at risk of a move into care.

With an overall focus on improving the 'voice, choice and control' of older people with high support needs, local developments included:

- Transport options to enable older people with high support needs to participate in community life, maintain personal networks and reduce social isolation, particularly in rural areas
- Improved information for older people with dementia and their carers
- Person centred approaches to improve voice choice and control for older people with high support needs in care homes
- Developing a neighbourhood focus for independent living to allow older people with high support needs to remain connected and involved while living at home in the community
- Involving older people with high support needs in service planning through the planning of an enablement service
- Increasing the voice of older people with high support needs in planning for discharge from hospital and in improvements in the provision of information about support options

The social and political context

The ODI-SERI project has been carried out against the background of a worldwide financial crisis, a UK general election and a new UK coalition government planning the most widespread cuts in public service provision in a generation.

By October 2008, when the ODI-SERI programme was launched, Britain was already in the middle of the financial crisis, with Northern Rock having been nationalised in February of that year, and Royal Bank of Scotland (RBS), and Lloyds TSB / Halifax Bank of Scotland (HBOS) rescued by the government in October.

2009 was a year of general disillusionment with politicians following from the MPs expenses row. The general election in May 2010 resulted in a hung parliament and the formation of a Liberal-Conservative coalition government with a commitment to cutting departmental public expenditure by 20% to 40% by 2014.

The legislative and governmental framework

The ODI-SERI programme began life under a Labour government led by Gordon Brown and completed its work under the Liberal-Conservative coalition. The change of direction towards a 'Big Society', introduced by the coalition government, together with the constraints of greater restrictions on public expenditure, meant a discontinuity in the legislative and governmental framework within which the initiative operated with some significant changes in the direction of policy.

The overall approach to social care within which the ODI-SERI programme initially operated was set out in *Putting People First*, a ministerial concordat, published in December 2007, providing a shared vision and commitment to the transformation of Adult Social Care. *Putting People First* aimed to develop a mainstream system focussing on prevention, early intervention, enablement and 'high quality personally tailored services' that allowed people to have 'maximum choice control and power over the support services they receive'. *Putting People First* created a statutory requirement for local authorities, primary care trusts and other NHS providers to carry out Joint Strategic Needs Assessments (JSNAs). The idea was to provide an integrated approach to local service provision including hospital discharge arrangements, and provide universal information, advice and advocacy. Person-centred planning and self-directed support were to become mainstream with personal budgets for everyone eligible for non-emergency publicly funded social care support.

In February 2008 the Department for Communities and Local Government (DCLG), Department of Health (DH) and the Department for Work and Pensions (DWP) jointly launched the housing strategy, *Lifetime Homes, Lifetime Neighbourhoods*, the intention of which was to make it possible for older and disabled people to stay in their homes for longer. The strategy promised increased funding for the Disabled Facilities Grant and that first public housing and then all new housing would be built to *Lifetime Homes Standards* by 2011 and 2013 respectively.

In March 2008, the Office for Disability Issues (ODI) launched its *Independent Living Strategy*, a five year strategy bringing together new and existing policy initiatives to provide a coherent framework to make progress towards 'independent living' for disabled people including older disabled people. The concept of and practices associated with 'independent living' are not necessarily about doing things for yourself, but about having choice and control over support and equipment that people may need to go about their daily lives; and about having equal access to public services and opportunities including employment, transport, health, housing and the ability to participate in family, community and civic life.

In the target culture of the time, independent living was seen as addressing a number of the Labour government's Public Service Agreement (PSA) targets for 2008-11 including PSA 15: addressing individual disadvantage through sexual orientation, gender, race, disability, age, religion or belief; PSA 17: tackling poverty and promoting greater independence and well-being in later life; PSA 18: promoting better health and well-being; PSA 19: ensuring better care and PSA 21: building more cohesive, empowered and active communities. Independent Living also addressed a number of National Indicator (NI) targets for local authorities including NI 136, the number of people supported to live independently through social services and NI 139, people over 65 who say that they receive the information, assistance and support needed to exercise the choice and control to live independently.

Despite the growing financial crisis, *Carers at the heart of 21st century families and communities*, a cross-governmental strategy to help carers, published in June 2008, promised £1.7 billion by March 2011 for councils to support carers, including information, helpline and respite services with £255 million of new commitment associated with the strategy. The intention was that, by 2018, carers would be able to have a life of their own alongside their caring role and would not be forced into financial hardship by the need to care.

The Elbourne *Review of Older People's Engagement with Government* was published in November 2008 making recommendations to improve the voice of older people, including establishing a UK Advisory Forum for Older People and strengthening Older People's Action Groups (OPAGs) through links with regional government offices. The government response, *Empowering engagement: a stronger voice for older people*, published in February 2009, agreed to establish a UK Advisory Forum on Ageing with regional forums feeding into the national body.

In July 2009 the Labour government published a cross-departmental document, *Building a Society for All Ages*. Building on the first national strategy, *Opportunity Age* (2005), it set out a "refreshed" framework for cross government working and policy development based on older people's priorities. Key areas for future attention were identified and potential recommendations made which are now being taken forward through the Ageing Well Programme funded by the Department for Work and Pensions and Local Government Improvement and Development.

Building a Society for All Ages also heralded the key government green paper *Shaping the Future of Care Together* launched shortly afterwards. The green paper outlined the government's ideas for a National Care Service in England, with the right to have care and

support needs assessed in the same way and to pay the same proportion of your care and support costs no matter where you live. Ruling out funding from general taxation, the green paper proposed four possible options for paying for the National Care Service. *Pay for yourself* with no support from the state; *Partnership* with a set proportion of care costs paid by the state; *Insurance* with a fixed proportion of care costs paid by the state and the individual able to insure against the rest by instalments or a lump sum payment on retirement or death; *Comprehensive* with everyone who could afford to paying into a state insurance scheme.

After consultation following the publication of the green paper, a government white paper *Building a National Care Service*, was published in March 2010. The white paper outlined the vision of a National Care Service that is universal and free when people need it, would ensure choice and control with nationally consistent eligibility criteria for social care enshrined in law and with personalised care and support through a personal budget. The National Care Service would be funded through the *Comprehensive* option and Disability Living Allowance and Attendance Allowance would be protected.

In November 2009 the Labour government introduced the Personal Care at Home Bill which proposed removing the restrictions on the length of time free personal care was available at home and would "provide support and financial relief to 400,000 older people with the greatest care needs, including those people with conditions like Parkinson's, dementia and motor neurone disease." The Bill became law as the Personal Care at Home Act in April 2010 but was amended by the House of Lords so that its provisions could not be implemented without a further vote in both the House of Lords and House of Commons. The coalition government has indicated that it would not implement the provisions of the Act but would instead set up a commission to consider the long term funding of social care.

One of the last pieces of legislation affecting the lives of older people with high support needs, introduced by the Labour government, was the Equality Act which became law in April 2010. The act outlaws both direct and indirect discrimination in the provision of goods and services on various grounds including disability and age. The provisions of the Act extend to health and social care but the provisions will be implemented in secondary legislation which, in the case of age discrimination in health and social care, will probably not be activated until 2012. There is pressure to make exceptions of decisions by medical staff and some age differentiated services in public health.

Following the general election in May 2010, the Labour government was replaced by a Liberal-Conservative coalition government.

In July 2010 a Commission on the Funding of Care and Support was set up by Secretary of State for Health, Andrew Lansley. The commission, which is chaired by Andrew Dilnot and due to report by July 2011, will make recommendations on how to achieve an affordable and sustainable funding system for care and support for all adults in England, both in the home and other settings. The commission will consider options for funding including voluntary insurance and a 'partnership' model between the state and the individual.

In July 2010 the coalition government launched its Ageing Well programme. Ageing Well, announced by Minister of State for Pensions Steve Webb, is designed to support local authorities to improve their services for older people. Ageing Well reflects the government's desire to shift power from Westminster to local people and their communities. The government will encourage local authorities to take the lead and to work in partnership with other local organisations, and older people, to develop 'imaginative' approaches to the issues faced by their particular communities. The programme provides peer group support and challenge for local managers and a series of 'master classes' to aid development.

Also in July 2010, the coalition government published the white paper 'Equity and Excellence', its vision for the future of the National Health Service. The radical plans included removing levels of health service management, including Primary Care Trusts (PCTs), devolving commissioning to General Practitioners (GPs) and their teams and the establishment of an independent NHS Commissioning Board. The intention is 'to put patients at the heart of the NHS through an information revolution and greater choice and control' with shared decision making as the norm, encapsulated in the maxim '*no decision about me without me*'. Patients will have greater control over their own care records and be offered a choice of GP practice, and consultant-led team. A new consumer champion, HealthWatch England, will be established within the Care Quality Commission (CQC). The long term impact on older people with high support needs, of these and other far reaching changes proposed in the white paper, is difficult to assess.

The coalition government has made, or plans to make, a number of significant changes to the pensions and benefit system. From April 2011 the state pension will increase in line with whichever is the greatest of earnings, price inflation or 2.5%. At the same time the measure of price inflation will change from the Retail Price Index (RPI) to the Consumer Price Index (CPI). CPI is generally 1% below RPI. The State Pension age is set to rise to 66 for both men and women by 2020.

In October 2010, the Secretary of State for Business, Vince Cable, and the Minister of State for Pensions, Steve Webb, announced the future intention to replace the current contribution based £97 per week state pension by a universal (citizen's) pension worth about £140.

In July 2010 Iain Duncan Smith, Secretary of State for Work and Pensions, launched the DWP *21st Century Welfare* consultation document, seeking to replace all benefits for people of working age by a single simplified working age benefit or universal credit. The consultation did not include benefits for older people with high support needs. The benefit reforms are informed by the work of the Centre for Social Justice, outlined in the next section.

In November 2010 the coalition government published *A Vision for Adult Social Care*, outlining its commitment to reform the system of social care in England to provide much more control to individuals and their carers by: breaking down barriers between health and social care funding to incentivise preventative action; extending the greater rollout of personal budgets to give individuals and their carers greater control and purchasing power; and using direct payments to carers and better community care provision to improve access to respite care. Together with an associated consultation document *Transparency and*

Outcomes, the 'vision' document will lead to a Care and Support white paper at the end of 2011 and a Social Care Reform Bill in the first quarter of 2012.

December 2010 saw the launch of the Localism Bill by Secretary of State for Communities and Local Government, Eric Pickles. The Bill contained a package of reforms designed to devolve greater power and freedoms to councils and neighbourhoods, establish new rights for communities, change the planning system and give communities control over housing decisions. The Government's intention was that the legislation would help build the 'Big Society' by radically transforming the relationships between central government, local government, communities and individuals.

The idea of the 'Big Society', with greater involvement by individuals, voluntary agencies and charities and a reduced role for the state through central and local government, is a key plank in the coalition government's reform programme.

Despite the change in government during the period of the initiative, one of the themes or directions of travel that has remained constant is the desire to pursue the personalisation agenda particularly in relation to social care. Even in its most general sense this should translate into enabling older people with high support needs the opportunity to have a greater degree of voice, choice and control over their own lives through the use of personal budgets and direct payments and access to more personalised or relationship centred care and support – leading to an improved well-being and quality of life.

Reports, Reviews and Guidance

During the period of the ODI South East Regional Initiative, in addition to the legislative and governmental framework within which the initiative operated, outlined above, a number of reports, reviews and guidance documents were published influencing the thinking about how best to help older people with high support needs achieve independent living.

This section reviews some of the key thinking about older people with high support needs in reports reviews and guidance during this period.

A number of key issues have been raised. These include

- Enabling the voice of older people with high support needs to be heard
- What older people with high support needs actually want and need
- The diversity of the population of older people with high support needs
- What is meant by independent living and how it can be achieved
- The value of personalisation in achieving independent living by older people with high support needs
- The importance of appropriate housing, neighbourhoods and communities
- The value of adaptations and assistive technology
- Appropriate home care and care home care
- The importance of available transport
- Financial constraints on provision for older people with high support needs

Older people's voice

One of the most important issues in helping to promote independent living among older people with high support needs is to ensure that the voice of the older person is heard. There is a strong feeling that the voice of the older person themselves is very rarely heard. (Crosby and Clark, 2008).

“...the voices of older people with high support needs are so quiet as to be practically silent or indistinguishable from the other people who speak on their behalf” (Bowers et al, 2009)

Given the special difficulties in self expression faced by some older people with high support needs, particularly those with dementia or other mental health problems how can those views best be heard?

Allowing the voice of older people with high support needs to be heard – advocacy and self-advocacy

Self advocacy implies that the older person is able to speak up for themselves and, while it is the preferred option, this may not always be possible. Self-advocacy for older people with high support needs may involve an element of advocacy by a third party (Community Care, October 2009)

A 2009 SCIE report, *Personalisation and learning disabilities: A review of evidence on advocacy and its practice for people with learning disabilities and high support needs*, (SCIE, 2009) outlined five approaches that non-directed advocacy might take.

Approaches to advocacy for high support needs

Advocacy with people with high support needs can suggest questions about whether the person has instructed a third party to raise issues on their behalf. Joel Rasbash (2005) and Chris George (2005) discuss different forms that non-instructed or non-directed advocacy might take and agree advocates should always start by assuming the person can communicate their wishes in some way. If this is not possible, there are a number of approaches available, as follows.

Rights-based approach

A rights-based approach is useful when an advocate has to act quickly with little time to get to know the person. It can give them confidence to focus on civil, moral and legal rights, many of which are set out in law. This approach encourages others to question whether the person is being treated fairly and without discrimination but there can be problems if the person's rights are unclear or conflict with each other.

There is a danger that, by focusing purely on rights, the advocate may miss out on the opportunity to find out about the person as an individual.

Person-centred approach

Person-centred approaches acknowledge that, despite a formal means of communicating what they want, the ways a person responds or expresses feelings can contribute to decision making. This means spending time with the person and often involves a 'circle' of support made up of people who know the person well and who work together to give them a 'voice' and involvement in planning. This could involve finding out how the person might be indicating 'yes' or 'no', looking at when and where they do this, any patterns or consistencies and whether people respond to or recall the consequences of their 'choice'

Watching Brief approach

The Watching Brief was devised by Asist Advocacy in Staffordshire (see www.asist.co.uk). It provides a framework for an advocate to ask the decision maker a series of questions based on eight quality of life domains, and provides clarity about why these questions are being asked.

Witness–observer approach

With a witness–observer approach, the advocate does not make judgements or assumptions but merely reports facts based on observations. This can often highlight things that may have been missed by others, for example lack of stimulation, dislike of activities or the possible communication value of certain behaviour or actions.

Best interest approach

Describing advocacy as 'best interests' might imply that a person who cannot instruct an advocate has a purely passive role in the decision-making process. However, the requirements of best interests counter this. Decision makers should encourage the person to take part in the decision, try to establish their views (based on past experiences, their beliefs and values and any other factors), involve others and avoid restricting their rights. This offers a clearer framework for decision making.

However, any non-instructed approach may add to the confusion over advocacy and the role of advocates. In practice, most advocacy with people with high support needs is a combination of all four, which may be described as different points on a continuum of non-instructed advocacy approaches. This is an attempt to balance the person's human and civil rights with an understanding of what appears to be important to them and what things might look like from their perspective.

What older people with high support needs want and need

The qualities that are important to people as they grow older include companionship and friendship; sharing common interests; availability of support and personal care; freedom from fear of isolation, loneliness and danger; social activity and easing of responsibility for daily chores such as house cleaning, cooking and gardening. (Crosby and Clark, 2008)

The Forgotten Age, a 2010 review from the Centre for Social Justice, provided an extensive overview of the issues facing older people, including older people with high support needs. The key social care problems facing older people including issues around care at home, personalisation, and the rationing of services to anyone other than those with the greatest

need. There is often a lack of forward planning for the likely financial and care needs of older age. (Centre for Social Justice, November 2010)

Diversity

Older people with high support needs are not homogeneous and there is great diversity in characteristics, personal circumstances and need.

High support needs can increase with age and so overall future demand for services is often estimated by analysing and projecting the numbers of the oldest old, for example those aged 85 and over. For men, life expectancy at age 65 has increased from 12.97 years in 1981 to 15.94 years in 2001 but the proportion of those final years that is spent healthy has fallen from 76.6% to 72.9% and the proportion disability free has fallen from 58.4% to 55.3%. For women, life expectancy at age 65 has increased from 16.92 years in 1981 to 19.03 years in 2001 but the proportion of that time spent healthy and disability free has held steady or increased. (Falkingham et al, October 2010)

Excluding residential care, for households where the key reference person is aged 85 and over in the UK, 63% live in their own homes, 29% rent from social landlords and 8% rent privately. 410,000 older people were living in care in 2004 and 170,000 receiving personal care at home in 2010, of whom over 50% pay for some or all of the care. (Joseph Rowntree Foundation, October 2010)

Local service providers need to be aware of local diversity and shape universal and targeted services accordingly. A 2008 report by the Audit Commission indicated that only one third of councils are well prepared and recommended that targeted services should focus on the underlying causes of dependency and tackle stereotypes and myths. (Audit Commission, 2008)

Black and minority ethnic groups are not evenly spread geographically. Individual groups tend to cluster in particular localities. In 2007 just under a quarter (24%) of the Bangladeshi population of England and Wales lived in the two London boroughs of Tower Hamlets and Newham and over half of all black ethnic minority groups (Black Caribbean – 53%, Black African – 57%, Other Black – 53%) lived in London. Black and minority ethnic groups are also, in general, younger than the majority white population. From 2016, however, the numbers of the older BME population of England and Wales will begin to rise rapidly and each local authority will need to be fully aware of the diversity of its own local older population. (Lievesley, CPA, July 2010)

Independent living

In the context of older people with high support needs, independent living means that the older person has 'voice choice and control' over their care. It is not the same as 'living independently' but this is not always understood.

Reported in its October 2010 round up review, *Older people with high support needs: how can we empower them to enjoy a better life* (Blood, 2010), Joseph Rowntree Foundation

challenge the assumption that home based living would, wherever possible, be the ideal for older people with high support needs. They argue that living in your own home does not, in itself, promote 'independent living', just as living in a communal setting does not necessarily preclude it. The earlier Joseph Rowntree study *Older people's vision for long term care* (Bowers et al, 2009) had emphasised the difficulties of older people with high support needs achieving voice choice and control in the care home setting. This remains a controversial and contested area, with little longitudinal evidence or examples of alternatives to institutional care for older people with the highest level of support needs.

Key issues in the promotion of independent living are: affordability; navigating the system; dementia and mental capacity; communal tensions; social isolation; recruiting and retaining a skilled workforce; involving and supporting carers; care communication and choice at the end of life.

The National Development Team for Inclusion (NDTi), in 2010 developed an *Independent Living Readiness Check*. This 'readiness check' outlines a series of criteria, based on what older people are saying and what local partners commissioners and providers are doing, to achieve the six principles of independent living: increase voice; ensure equal access; enable choice and control; enable participation; join it up strategically and promote a new way of thinking.

The principles of independent living, and a set of resources for professionals to help older people with high support needs to achieve independent living, were published on the web resource www.independentlivingresource.org.uk jointly hosted by NDTi and CPA.

Personalisation

The personalisation agenda, and the provision of individual budgets and direct payments to older people with high support needs to control their care, is seen by many as a key driver to achieve independent living but this approach is not without its problems.

The *national evaluation of the Individual Budgets pilot programme (ibsen)* reported, in 2008, that individual budgets were typically used to purchase personal care, assistance with domestic chores and social, leisure and educational activity. People receiving individual budgets were more likely to feel 'in control' of their daily lives but little difference was found in the average cost of an individual budget compared with conventional care. Individual budgets were cost effective but there were difficulties in devising processes to gauge the level and appropriate use of budgets and also legal and accounting barriers to combining funding streams.

There were concerns surrounding personal budgets and risk. Potential risks included poorer quality services particularly untrained, unregulated personal assistants, budget management and employment responsibilities, misuse of funds, financial abuse by family or paid carers, neglect or emotional abuse, physical harm, breakdown of care arrangements and contingency planning, and local authority responsibility for backup if arrangements fail.

A national report *Financial management of personal budgets*, published in October 2010 by the Audit Commission, recognises the difficulties faced by local authorities in implementing personal budgets and gives guidance on how local authorities can establish an appropriate framework to allowing maximum flexibility while avoiding opportunities for fraud.

The Department of Health report *Putting people first: Personal budgets for older people – making it happen* (DH, January 2010) outlined a set of case studies, a progress report and key policy drivers. It was reported that 55% of older users of personal budgets have chosen a ‘virtual budget’ and 44% have chosen direct payments.

In October 2008, the Commission for Social Care Inspection (CSCI) published *Cutting the Cake Fairly*, a report on eligibility criteria for social care. The report highlighted the tensions between the Fair Access to Care Services (FACS) funding framework and the personalisation agenda, the former being focussed on standardisation, consistency of treatment and explicit decision making and the latter focussed on self-assessment and individual choice and control. The report however identified the main problem as the overall under-funding of social care provision rather than shortcomings in the FACS system.

Think local, act personal (SCIE, November 2010), a sector-wide partnership agreement led by SCIE and endorsed by over 20 other organisations supported a preventive, community-based and personalised approach to care and support as outlined in ‘Putting People First’, the Labour government’s December 2007 ministerial concordat.

The agreement emphasises the need to learn from the attempts at implementation of PPF since 2007 enabling adults and older people to remain living at home, maintain and gain employment and ‘make a positive contribution to the community’. It sets out a framework for implementation with small scale independent and voluntary sector micro-providers and social enterprises offering community based affordable support to individuals and small groups and ‘direct payments’ as the preferred personalisation delivery model for most.

Housing and neighbourhoods

There is widespread recognition that appropriate housing and the existence of inclusive and supportive neighbourhoods and communities are key drivers in determining well-being and a sense of engagement or otherwise with ‘neighbourhood’ and the ability to achieve independent living for older people with high support needs.

The 2008 *Lifetime Homes, Lifetime Neighbourhoods* strategy promised increased funding for the Disabled Facilities Grant and that all new housing would be built to Lifetime Homes Standards by 2013.

A useful report, *More Choice, Greater Voice: A toolkit for producing a strategy for accommodation with care for older people*. (Appleton, 2008), provided a template and toolkit to produce a local strategy for accommodation with care for older people. The report highlights the following key influencing factors:

- The majority of older people will live until the very end of their lives in general housing and may need adaptations and other forms of help and advice to cope with their homes.
- An increasing proportion of older people are homeowners (around 75-80% in most places) and they will be reluctant to transfer into rented accommodation in old age and see the value of the equity in their homes eroded.
- Much specialised accommodation is in sheltered housing, some of which is now quite old and lacks the space standards and facilities now accepted as normal.
- The average age of those living in such accommodation has moved upwards very rapidly in the last two decades, bringing higher levels of need for support that the design of these buildings does not always allow.
- Some sheltered schemes have seen the retreat of amenities, such as shops, access to doctors and pharmacy and proximity to public transport – making independent life for their residents more difficult.
- New models of enhanced and extra care housing have emerged, offering not only the possibility of supporting higher levels of dependency but also an environment for a lively and active old age.
- Local authority residential care provision is generally housed in buildings that are now showing the limitations of their design concepts, even when the fabric is in good condition. Whilst dedicated staff add enormous value to the lives of those who live in such homes the pattern is inherently institutional. Local authorities have generally found it unfeasible to continue the direct provision of such accommodation.
- In the private sector the provision of traditional residential care in relatively small units is financially precarious and many providers continue to leave the market.
- While the nursing home sector continues to provide a context for the care of the more physically dependent and mentally confused older people, the steadily rising cost makes it imperative that other solutions are explored.

- The significant growth of the oldest section of the older population brings with it marked increases in the number of those with dementia and other forms of cognitive impairment. For them there is a desire to provide something more than the alternative of being cared for at home or going straight into a nursing home. While the support of older people with such conditions in sheltered housing is sometimes difficult, there are housing based models – often involving the use of new technology to manage risk – where a good quality of life can be achieved.
- Expectations among older people will continue to increase, in relation to their physical surroundings and access to facilities – but also in their right to be consulted and to participate in decisions that affect their lives.
- Traditionally, the attention of the local authority has been focused almost exclusively on identifying and meeting the accommodation and care needs of those who met the eligibility criteria for statutory funding. An increasing proportion of older people have the financial resources to fund their access to accommodation and care but do require information, advice and assistance in making sound decisions. The strategic orbit of the local authority and its partners should include these self-funders, the facilitation of appropriate accommodation and care options for them and the provision of information, advice and assistance

Adaptations and assistive technology

The importance of small scale housing adaptations and the use of assistive technology to help promote both independence and independent living is increasingly emphasised.

Ways to promote independence include timely adaptations such as grab rails, stair lifts, walk-in showers and ramps; personalised or self directed support whereby people can plan services tailored to their own needs through individual budgets and direct payments; building homes to 'Lifetime Homes' standards; telecare assistive equipment linked to a control centre; telehealth remote monitoring of vital signs; rapid repair and 'handyman' services; helping to keep warm through advice on healthy eating and exercise, home heating, energy efficiency; advice and information on all aspects of housing including maintenance, adaptation and equity release. (Crosby and Clark, 2008)

Each year the government lays before parliament a schedule of supported assisted technology research and development covering such areas as mobility in the community, recovery following stroke, support for people with a cognitive impairment for example dementia, improving online accessibility, older people living well, bringing healthcare closer to home and technology to support walking. (DH, 2008)

Home care and care home care

Older people's vision for long-term care (Bowers et al, 2009) emphasised the imbalance of power between care providers and care receivers and generally low expectations. A move to care can be triggered by bereavement, poor or unsuitable housing, concerns about health, inadequate care arrangements at home or the concerns of others. Home care arrangements may collapse following a move to care, so the move becomes a one way route with no possibility of return. Care homes are increasingly seen as a location of last resort.

The care debate is dominated by a mixture of global trends and individual support needs – an ageing population, money and the market. The range of possible benefit and care options is confusing for both older people and carers and individual / personal budgets tend to exclude older people in care homes and other supported accommodation.

Older people with high support needs are often seen as commodities rather than consumers with rights. 'Keys to a better life' are seen as: personal identity and self esteem; personal authority and control; meaningful relationships; meaningful daily and community life; home and personal surroundings; personalised support and care.

Transport

Older people, particularly those with high support needs, are often disproportionately reliant on locally provided transport options.

The Department for Transport's *Resource guide for local authorities: transport solutions for older people* (Department for Transport, February 2010) provides a valuable guide to local authorities of some available transport options for older people.

Free off-peak concessionary bus fares are available to older men and women when they reach the pension age of an older woman born on the same day. These national concessions can be supplemented locally by companion passes, free travel on other than buses and peak-time travel.

The higher rate mobility component of Disability Living Allowance, if taken up before age 65, extends beyond age 65 and allows aid with the hire or hire purchase of a car, powered wheelchair or scooter, Blue Badge parking and exemption from vehicle excise duty and road tolls.

The guide notes that details of door-to-door and other community transport schemes, run by voluntary organisations and supported by the Community Transport Association, (CTA) can be found at www.a2binfo.net, while taxi cards, shared taxi and taxi-bus schemes offer the possibility of greater flexibility.

Financial constraints on the provision of care

One of the most difficult future challenges facing older people with high support needs and their supporters and carers is the tightening of financial budgets at a time when overall demand for services is likely to increase.

Social care for older people with high support needs is provided by local councils in England paid by Revenue Support Grant supplemented from Council Tax and other local sources. Demand is controlled through eligibility criteria and means testing (eligibility thresholds). Because of changing demographics, to maintain 2007/8 levels of service and eligibility standards to 2025/6 for social care services for older people would require a 3.5% per annum increase in expenditure in real terms. The most likely scenario is 6.7% reduction in expenditure from 2010/11 to 2011/12 leading to tightened eligibility criteria with increased personal costs and reduced service take-up for individuals. (PSSRU, March 2010)

The Audit Commission report *Under Pressure, tackling the financial challenge for councils of an ageing population* noted that social care spending has increased by 46% from 2000/01 to 2007/08 but carers aged over 60 provide twice as much value in care as public expenditure on care services for older people.

Councils need to fully understand the age and social profiles of their population in order to provide appropriate services and there are big variations (up to three-fold) in council expenditure per person on certain services.

Small investments in housing and leisure can reduce or delay care costs and improve wellbeing. The main causes of need for social care are poor housing and environment; health and mobility problems; breakdown of informal support and social isolation. (Audit Commission, 2010)

Conclusion

The ODI South East Regional initiative has taken place in a period of great change and flux. Current financial circumstances, and a number of recently introduced central government ideas and initiatives, are likely to have a significant future impact on the lives of older people with high support needs. Health service reforms for example, especially the introduction of GP led commissioning, are likely to have a major future impact.

In both the legislative and governmental framework within which the ODI-SERI initiative operated and the thinking outlined in reviews and reports, one of the key elements was the taking forward of the personalisation agenda and the promotion of the increased use of personal budgets and direct payments.

Personalisation is a persistent theme that has survived the change in political direction.

There remains a commitment to increasing the voice choice and control of older people with high support needs. This commitment has however increasingly been taking place in a climate of recognition of future restraint on the availability of funds to provide the necessary support through public bodies. This has led to an increased emphasis on self-reliance and local community support through volunteers and third-sector bodies as part of the notion of the 'Big Society'.

Despite the commitment to greater voice, choice and control for older people with high support needs, the concept of *independent living* as meaning greater *voice choice and control* is still not always understood in the broader community, even among professionals. There are very few specific policies, in relation to older people with high support needs, that go beyond the boundaries of health and social care.

There is, however, an increased understanding that older people with high support needs do not form a homogeneous group and that there is a need to be aware of local diversity in order to provide appropriate support and services.

At the same time, advocacy and self-advocacy remain key elements in making it possible for the voices of older people with high support needs to be heard.

The current period of economic restraint, with possible future changes to available services and benefits, means a period of uncertainty for older people with high support needs. It remains to be seen whether the change in direction towards a 'Big Society' will be able to adequately satisfy the needs of this vulnerable group.

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