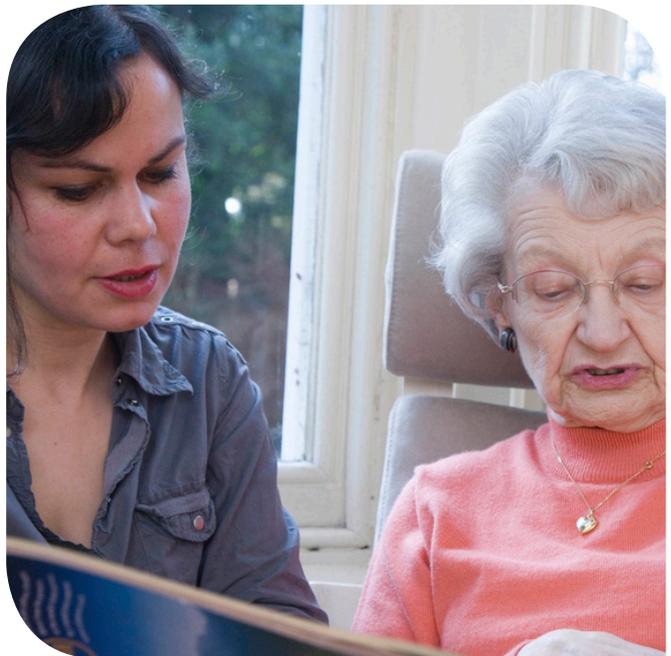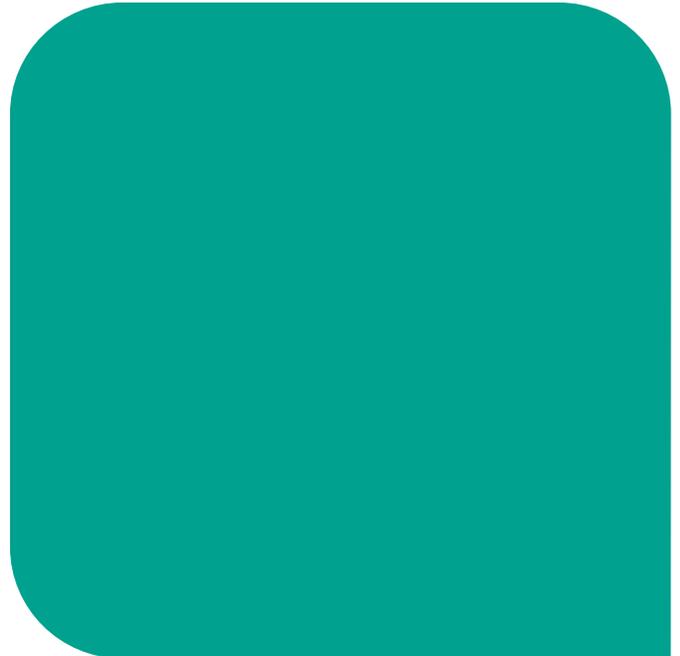**sce** social care
institute for excellence

Co-production and participation: Older people with high support needs

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Contents

Key messages

*'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)*

- Service providers need to understand that as the demographic of this group is changing and growing, and they need to adapt their services, and their co-production initiatives, accordingly.

- In 2007, 1.3 million of the population were aged over 85 and around 40 per cent had some form of severe disability. This group is projected to grow to 3.3 million by 2033.

- The group of older people with high support needs is becoming increasingly diverse with increasing representation of people from black and minority ethnic communities, people from lesbian, gay, bisexual and transgender communities and groups such as people with learning disabilities living longer.

- Service user and carer participation is high on the agenda in social care but the practice, information and guidance around older people with high support needs remains limited.

- There are examples of good practice in co-production and participation with older people with high support needs, which are identified in this report and show how barriers to the development of co-production and participation can be overcome.

- The benefits of involving users in their own care decisions and service improvement are well documented and are referenced in this report. It is fundamental to a sense of wellbeing for the individual and results in better quality in both policy and service development and also has benefits for everyone involved in social care provision including practitioners and carers.

Introduction

> *'The evidence base on the participation of older people with high support needs is very limited.' (Manthorp 2010)*

This report gives a summary of a review of literature and a small-scale survey of good practice on the participation and co-production of older people with high support needs.

This is a key issue for all involved in social care from policy makers through to frontline practitioners but the report will be of particular interest to

- commissioners of social and health care services,
- people working in housing provision
- service users and others developing the co-production/participation agenda in care provision and service development.

The policy background

Service user and carer participation is strongly on the agenda in social care, in the main because of the persistence and drive of the user and carer movements. But despite the rhetoric of involvement and participation, in most cases participation remains limited for older people (Blood 2010a and Katz *et al* to be published).

A key theme of the modernisation agenda in relation to older people is the importance of user-centred approaches – especially in the development and provision of services (Latto and King 2004). The 'New Labour' government of 1997 promoted ideas of 'active citizenship' and 'democratic engagement', pledging to listen to the voices of older people.

The Better Government for Older People pilot projects were set up in 1998 in the UK with the broad aim of involving older people in the inter-agency strategies that impact on their lives. Similarly driven initiatives such as The Millennium Debate of the Age, sponsored by Age Concern England the following year, focused attention on raising awareness of the ageing population. It ensured that government policy developed accordingly, with one such development being the National Service Frameworks. By the start of the new millennium 'listening to older people' was firmly established on both national and international policy agendas (Scourfield 2007).

Subsequent government strategies and policies in England such as the Social Exclusion Unit's report, *A sure start to later life* (SEU 2006) addressed social inclusion among older people. *Putting people first* the following year focused on prevention, early intervention, enablement and a 'high quality personally tailored service' that allowed people to have 'maximum choice and control over the support services they receive'.

In 2008 the housing strategy Lifetime Homes, Lifetime Neighbourhoods was launched to enable older and disabled people to remain in their homes for longer. Later that year two other key policy papers were issued. The first was the *Independent living strategy* which defined independent living as 'having choice and control over the assistance and/or equipment needed to go about your daily life' and 'having equal access to housing, transport and mobility, health, employment and education and training

opportunities'. The second was the White Paper *Communities in control: Real people, real power* (CLG 2008), with a strong national policy drive towards citizen involvement.

Similar policy objectives and initiatives around the participation of service users may also be reflected in other parts of the UK.

For example, although it does not explicitly reference older people with high support needs, legislation in Northern Ireland (Health and Social Care Reform Act 2009) requires health and social care policy makers, commissioners and service providers to ensure that service users and carers are consulted and that the mechanisms for doing so are published in a consultation scheme. This is more widely known under the umbrella term Personal and Public Involvement (PPI).

These developments highlight central government's commitment to giving older people a stronger voice in public policy and ensuring that their views prompt change. However, this shift in approach has led to debates about how to ensure that the diversity of older populations can be represented in the decision making process. Older people with high support needs are one of the groups currently largely excluded from participating in decisions about service delivery and development, and this highlights the need to share the lessons from the good practice that does exist in order to deliver choice and control over services and support for this group of people. Among this group, those who are physically frail are often considered unable to have a major impact on service planning and development (Barnes and Bennett 1997). Studies indicate that physically frail older people have low expectations and can feel intimidated if they express dissatisfaction about their experiences of services (Barnes and Bennett 1997). This includes older people in care homes and other supported accommodation who can find it challenging to articulate their feelings and – in those settings – can be particularly vulnerable (Scourfield 2007). A review of initiatives to involve older people in community care planning as far back as 1994 found few examples of the involvement of frail older people in comparison to active older people who were participants in pensioners' action groups and older people's forums (Thornton and Tozer 1994). This situation has changed little in the last 18 years.

The White Paper *Caring for our future: reforming care and support* (DH 2012) continues Government's commitment to co-production and 'making it real'. It's intention is to ensure that people who use services 'will have control of their own care and support, so they can make decisions about the options available. People will not have to fight against the system: health, housing and care services will join up around them. The Government will work with partners – including people who use services and through the Think Local, Act Personal partnership. Specifically, Government will develop and test options for a potential new assessment and eligibility framework, in consultation with people who use services.

The aims of this report are to:

- identify any barriers to the participation of older people with high support needs
- map current and past good practice for increasing the participation of older people with high support needs

- identify new approaches to involve older people with high support needs, including the use of technology.

The remit was to focus on housebound older people and those who live in care homes. However, increasing numbers of older people with high support needs live in privately owned or rented properties or extra care housing, and they are not necessarily all housebound. This report includes some discussion on these aspects.

The evidence

This is not an exhaustive literature review. It is based on an initial SCIE review of 'participation' in June 2010 and is not intended to present the full range of debates, policies and practice examples. Instead it provides a summary of some of the messages that can be used to inform thinking. Because of the lack of topic-specific material on participation *and* older people with high support needs a second supplementary review was undertaken to further source topic material

A number of issues concerning the evidence used in this study are listed below:

- The evidence base for this review is limited as research and practice material is either focused on the participation of older people generally or on older people with high support needs with no reference to participation. A combination of the two topics is rare.

- It is not always clear that the references to good practice, research, policy, and participatory methods have involved older people with high support needs – unless specific reference is made to conditions such as dementia or communication needs.

- There is limited data on older people with high support needs, especially at regional and local level. In addition, most of the data exclude those living in institutional care and does not easily break down by key characteristics such as ethnicity and sexuality.

- Although there is a significant body of literature about engaging with people living with dementia, there is a need for more work in this area. However, the views of older people with high support needs from black and minority ethnic (BME) and lesbian, gay, bisexual and transgender (LGBT) communities are particularly under-represented.

- The improved life expectancy of people with learning disabilities such as Down's Syndrome means they are more likely to live longer and experience old age and dementia. However, evidence is limited on the needs of older people with learning disabilities and their carers.

- With the exception of a few sources – such as the ONS/DWP *Focus on Older People* (ONS 2005) – much of the data on the older population is based on those aged 65 and over. This treats older people as a homogenous group. It is

uncommon to find data looking specifically at people aged 85 and over and more research is needed in this area.

- There is a lack of research on the experiences of those who acquired their disability in later life compared to those with pre-existing disabilities.

- Not enough is known about the use or effectiveness of different tools such as life history in promoting a more personalised approach to care.

- Research is limited on the housing and support needs of LGBT older people, as well as individuals with multiple and complex needs who are at risk of homelessness.

- More research is needed in the 'housing with care' context of caring for people with dementia.

Defining 'older people with high support needs'

> *'This is not a homogenous group. By definition "older people with high support needs" fall into two strands of disadvantage – age and disability.' (Blood 2010b)*

Over the next 25 years the 'pensionable age' population will grow by 3.8 million in the UK and the number of people over the age of 85 – where support needs are the highest – will more than double (ONS 2009). More people are living for longer, and with higher levels of severe disability at older ages (Centre for Population Change 2010). Seventy-eight per cent of women and 70 per cent of men over the age of 85 have a limiting long-term illness – and about a third (36 per cent of women, 32 per cent of men) are in persistently poor general health (Crown Copyright 2003).

Reaching a consensus on definitions can be problematic. Both 'older' and 'high' are used as relative terms and are applied differently by health practitioners, social care workers, older people or their families (Blood 2010a). In the context of the social model of disability, an older person who is physically frail with a chronic condition or various 'co-morbidities' – other conditions in addition to their main disease – might not have high support needs if they live in accessible housing with assistive technology, and are supported appropriately in the community. Therefore the point at which an individual may need support is prompted by a complex combination of medical, social and personal circumstances. 'The need for support is not simply a personal characteristic. It depends upon the nature of the society and communities we live in' (Garwood 2010).

By definition 'older people with high support needs' fall into two strands of disadvantage – age and disability (Blood 2010b). Other equality strands (gender, ethnicity, religion and belief, lesbian, gay, bisexual and transgender people, and poverty) may be over-represented in this group too. Where an older person falls within a number of equality strands their voice, choice and control can be compromised because of the structural inequalities inherent in services (Blood 2010b and Beresford and Harding 1993).

Age

The age range of the over 85 age group covers two or even three generations. There are over 10,000 centenarians in the UK. Of this 'oldest old' age group – which is the fastest growing age group, representing 2.1 per cent of the UK population – 40 per cent of people have some form of 'severe disability', determined by their ability to perform activities of daily living (ADLs) (Centre for Population Change 2010). While many people in their 90s are in good health and active, there are some homeless people or refugees who – due to the early onset of chronic health conditions – might be included in this category in their 50s. In some ethnic groups morbidity can present itself relatively earlier than within the indigenous older population. Therefore, despite being a good pointer, age cannot in itself be used to predict whether a person is likely to have high support needs.

Disability

Older people with high support needs will meet the Equality Act definition of disability, which states that the individual will have 'a physical or mental impairment and the impairment will have a substantial and long term adverse effect on his or her ability to carry out normal day-to-day activities' (Equality Act 2010) (Disability Discrimination Act 1995 in Northern Ireland). Within this group, some will have spent all or most of their life with a disability. Others will have acquired impairments late in life. Some disabled older people may generally be in very good health, but at any one time, there will be those recovering from a fall or operation, or in an acute phase of their condition.

Gender

Women are over-represented in the over 85 category. There is roughly one man to every three women aged over 90. Older women are typically more likely to live alone, be poor and to endure longer periods of morbidity. They are more likely than men to experience certain 'ageing' conditions such as osteoporosis –which is linked to fractures and falls (Blood 2010b) – and dementia. Older men have higher rates of morbidity and mortality from most cancers and heart disease and – particularly those from working class backgrounds – are at greater risk of untreated health conditions or social isolation (Blood 2010b).

Ethnicity

The proportion of the black and minority ethnic (BME) population with high support needs is relatively low in comparison to the indigenous older population. Population estimates for 2007 suggest that around five per cent of those over 85 in England and Wales were from ethnic backgrounds other than 'white British', but with huge local variations in this. Certain aspects common to BME populations can increase the likelihood of the need for more support. For example, there is an increased incidence of some conditions in certain ethnic groups, such as diabetes in south Asian communities (DH 2005).

Religion and belief

There is a higher proportion of people in this age group with religious and cultural beliefs than in the general population (Blood 2010b). This will inform the type of care individuals wish to receive. The diversity of the BME population in the UK can also be under-estimated. There needs to be more emphasis on providing services that accurately reflect the language, cultural and religious differences of frail older people from these different communities (Mold *et al* 2005).

Lesbian, gay, bisexual and transgender (LGBT) people

Older lesbian, gay and bisexual people have higher rates of specific health conditions and health-related behaviours such as smoking, drinking and mental health problems, than in the general population. Also, they may have less care available from their family (Blood 2010b). Support needs can be high as people may intentionally avoid accessing services and often avoid 'coming out' (Musingarimi 2008) for fear of discrimination

(Blood 2010b, Fallon *et al* 2010 and Langley 2001). Although the literature is sparse, it is a fact that transgendered people also face discrimination (Latto and King 2004).

Poverty

Income, housing status and occupation are likely to impact on older people's health outcomes and affect their access to care and support. This means that those from poorer socio-economic backgrounds are likely to be over-represented in the 'older people with high support needs' group (Blood 2010b). Access to services is relatively poor for particular groups such as gypsies and travellers. This can mean they are not known to services and experience higher rates of long-term limiting illness and poor psychological health (Blood 2010b and Lane and Tribe 2010). The generally accepted lower age boundary for older homeless people is 50, because they experience disability and ill health at a relatively early age (Branfield and Beresford 2010). Older people from these groups tend to experience 'premature ageing' caused by stress, trauma, poverty and barriers to services.

Learning disability

More people with learning disabilities live into later life. This group has high levels of particular healthcare problems as well as additional needs related to their disability, including sensory and physical impairments, autism and mental health problems (Emerson *et al* 2001).

Dementia and mental health problems

The number of older people developing a dementia is rising significantly as people live longer. In 2009, the National Dementia Strategy (DH 2009) estimated that there were approximately 700,000 people with dementia in the UK. That number is expected to double within 30 years. Older people with dementia can experience discrimination and be ostracised by other residents when they move into housing with care settings (Branfield and Beresford 2010). Depression – the most common mental health problem in later life – profoundly affects 2.4 million older people (Garwood 2010) and is linked to various factors including lack of participation in meaningful activity (Age Concern and Mental Health Foundation 2006).

Sensory impairment

It is estimated that one in eight individuals aged over 75 and one in three over the age of 90 have a serious – 'registerable' – sight loss (Fletcher *et al* 2006). High numbers of residents in extra care and sheltered housing have impaired sight (Garwood 2010). It is not clear how many people over 60 experience dual sensory impairment, but it is considered to be as high as two million (Hodge and Douglas 2007).

The equality strands described above highlight the diversity of this group of older people. However, there is a danger – in breaking the group of older people with high support needs into broad sub-groups – of overlooking the fact that many people fall into more than one, or even several categories. Multiple conditions and forms of discrimination can interact with each other. For example, an older person with HIV may

also have a sensory impairment, be a refugee from a black African background and experience mental health problems (Blood 2010a).

Housing contexts

Many older people with high support needs live in care homes and housing with care settings. In 2004 it was estimated that there were 410,000 care home residents in the UK (Blood 2010a and Office of Fair Trading 2005), with most residents aged 85 and over, and 75 per cent having a 'severe disability' (Blood 2010a). Thirty-three per cent of those suffering with dementia lived in care homes, and the remainder lived in the community (Alzheimer's Society 2007).

Care homes

The Joseph Rowntree Foundation's (JRF) review (Szczepura *et al* 2008), drawing together research on improving care in care homes as the needs of older people increase, identifies seven key themes:

- residents' and relatives' views on care

- clinical areas for improvement

- medication

- medical input into care homes

- nursing care in care homes

- interface between care homes and other services

- care improvement in care homes.

Other research highlights factors such as autonomy, choice, social need and physical and social environment. These are important aspects of promoting quality of life (Byrne and MacLean 1997, Cook and Stanley 2009, and Kane 2001). A study exploring the lives of eight older people in four English care homes revealed the disparities between the experiences of individuals. There was a divergence between those who had experienced an enriched existence with greater opportunities for meaning, purpose and satisfaction – which they termed 'living with care' – compared to other residents – who were 'existing in care' – being restricted by institutional regimes, and not able to express their voices or be heard (Cook and Stanley 2009).

Research about BME older people in care homes and the most effective forms of service delivery is sparse (Mold *et al* 2005). Advocacy is now being recognised as an important service. There has been a growing move to extend access to advocacy to care home residents so they can have a say in how services are run (Scourfield 2007). However funding is often a problem (Horton 2009). In 2007, Furness proposed that care homes should set up 'friends of the care home' groups as a way of promoting control and interdependence, encouraging better communication and participation, and improving relationships between staff, residents and their families and friends (Furness 2007).

Housing with care settings

This model of housing aims to address the housing, care and support needs of residents, whilst helping to promote independence, social wellbeing and quality of life (Callaghan *et al* 2009). While the principle of participation is generally well accepted in housing with care, knowing *how* to do this with people who have high support needs is another matter. The usual methods of engagement such as leaflets, questionnaires and meetings are not appropriate (Garwood 2010). Social activities are particularly valued by residents in these settings and can be especially significant in terms of social contact and helping individuals to nurture new friendships (Bernard *et al* 2004 and Evans and Means 2007). For frailer residents, participation in social activities is especially important and can have a significant impact on their quality of life (Croucher *et al* 2006). But mobility problems, frailty and sensory impairment can hamper participation (Croucher *et al* 2006, Evans and Vallely 2007, Stacey-Konnert and Pynoos 1992 and Croucher *et al* 2007), therefore it is essential to give staff or volunteer support and have a mix of older people with different dependency levels (Callaghan *et al* 2009). There is also evidence that older people with dementia can experience discrimination and be ostracised by other residents when they move to housing with care settings (Branfield and Beresford 2010).

Older people in the community

One of the most prominent developments in the second half of the twentieth century has been the increasing numbers of older people deciding to remain in their own homes.

The fastest growth has been amongst those aged 85 and over (Centre for Population Change 2010). Older people prefer to remain in their own home as long as support is provided. This independence depends on access to advice, information and practical support in and around the home and can also include having the home adapted as needs increase.

Older people frequently complain about the difficulty in getting up-to-date information about adaptations, services and assistive technology and this problem is greater for those with high support needs. Because of their vulnerability, older people with high support needs are not always able to negotiate the best options and need support to do this.

Participation – benefits and barriers

> *'Older people's definition of co-production is 'Local authorities, older people and older people's organisations working together to design and deliver opportunities, support and services that improve wellbeing and quality of life.'*
> (NDTi and Helen Sanderson Associates 2009).

Genuine participation is about having a voice and being heard by others – including professionals and family – in such decisions as moving to a care home, improving quality of life, or helping to promote inclusion.

Benefits

The opportunity to get involved in care decisions and service improvement discussions is fundamental to an individuals' sense of wellbeing (Evans and Vallely 2007). Where this does not happen, choice and control is compromised. Benefits from involving users and the public include:

- improved outcomes of treatment and care (Barnes and Bennett-Emslie 1997)
- services are more responsive to the needs of users
- individuals and communities build up a sense of ownership of services (Ridley and Jones 2002)
- users gain knowledge and self confidence (Thornton 2000)
- policy and service quality improves (Carter and Beresford 2000).

If public services fail to understand the needs of older community members from the older person's perspective and also fail to address these needs, older people will not achieve optimal quality of life, and services will not be cost effective.

Factors that older people say are fundamental to participation

According to a study commissioned by the Scottish Executive (Dewar *et al* 2004), older people identified the following as key elements for effective involvement:

- a proactive – not reactive – approach
- timely involvement to ensure views can influence outcomes
- involvement should be paced by the needs of those being involved rather than those of the organisation
- devolution of power by agencies and a willingness to work in partnership with older people
- clarity about the purpose and likely outcomes of involvement, as well as expectations of those being involved
- significance to the lives of community members
- senior management level commitment to involvement.

Other important factors include the need for an effective lead champion at a senior level supported by champions at all levels of the organisation, an anti-ageist culture sustained by training and supervision, and the need to ensure that outcomes are monitored (Audit Commission 2008).

Barriers

Barriers to participation are primarily to do with the negative and ageist attitudes of professionals and others towards older people. Meeting the costs of participation can also raise funding issues, and older people themselves often have low expectations of the effectiveness of involvement. Some barriers are listed below:

Lack of support for older people to develop personal skills

If older people are to make real choices about what kind of support and accommodation they prefer, they need an initial level of capacity-building or personal empowerment to explore the services that best suit them individually and to participate on their own terms (Carter and Beresford 2000).

Information

For older people to fully participate, it is essential that they are given information, advice and advocacy to be able to make fully informed choices about effective services (Granville *et al* 2011).

Practical support for older people

Providing – or paying for – transport to get to and from venues as well as help with payments and expenses (Carter and Beresford 2000). Finding accessible venues can also be costly and problematic, as even accessible meeting places do not have enough facilities for large groups of people.

Organisational barriers

A variety of organisational barriers exist, including poor shared understanding about involvement between different levels within organisations and across agencies. A lack of resources in terms of staff time and support can affect the capacity for older people to get involved in activities. It can be costly to ensure older people are included, in terms of meeting their accessibility needs and building in enough time for effective involvement. The culture of staff teams will also determine the way that care is delivered and this can be difficult to change. Strong leadership that provides a vision for age equality and a systematic approach to ensure that it is practiced through competent staff recruitment, supervision and appraisal is crucial in setting a positive and sustained staff culture.

Communication barriers between staff and older people

Staff are often ill-equipped to deliver person-centred care when dealing with people with dementia and those with other communication support needs. They need training, support and the necessary tools to understand what a particular individual may be trying to express through certain behaviour (Branfield and Beresford 2010).

A National Audit Office report (2010) found that there is no obligation for care homes to train their staff in communication with residents, and this is probably also the case in housing with care settings (Branfield and Beresford 2010).

Dementia specialists believe that the challenging behaviour exhibited by people with dementia is due to the frustration of not being able to communicate (Branfield and Beresford 2010). In a similar way, those who experience communication problems because of conditions such as a stroke or learning disabilities – and individuals who have cultural and language barriers – may also experience frustration at not being able to express themselves clearly (Branfield and Beresford 2010 and JRF 2004).

Communication support needs are less obvious and not as easily recognised as physical disabilities. Staff can find it difficult to understand the nature of a person's experiences, which can lead to false assumptions about the person's disposition, intelligence and mental health (Law *et al* 2007). It is often assumed that individuals are difficult to engage with in research or other processes (Granville *et al* 2011).

It is not always the case that people who cannot speak are impossible to engage with. Given that over 80 per cent of communication is non-verbal – through facial expression, gestures, body posture and eye contact – other forms of communication need to be explored (Chapman 2009).

Older people living in rural areas

Older people in rural areas face particular challenges – including finding it difficult to organise as a collective and getting peer support (Thornton 2000).

Inappropriate methods for engaging with people

In housing with care settings, usual forms of communication such as newsletters, meetings and surveys are not appropriate for engaging older people with high support needs, as they do not allow for poor mobility, sensory impairment and poverty. Programmes such as the **Enriched Opportunities Programme** are advocated in such setting.

Limited access to advocacy

Advocacy – alongside information and advice – empowers older people and encourages them to have their own voice. In the context of the provision of a specific independent advocacy service, advocates can ensure that a person's voice is heard, either by speaking for them or supporting them so they can speak for themselves. Many advocacy services have been reduced because of funding cuts (Horton 2009).

Consulting black and minority ethnic communities

Many black and minority ethnic groups have a negative view and distrust of local councils, and do not see them as independent enough from official authorities (Bousetta 2001). Individual black and minority ethnic older people also continue to experience language and communication problems that exclude them both from services and from becoming involved in making decisions about them (PRIAE 2005).

Balance of power

One barrier to participation is the failure to recognise the imbalances of power (Doel *et al* 2007). More power needs to be devolved from the centre to individuals and communities in order to make participation genuine for older people. Examples of real co-production where older people are working together in partnership with local authorities or voluntary organisations are rare.

Types of participation

Older people can participate as part of whole communities through civic forums, community councils, local area forums, committees and citizens' panels (Dewar *et al* 2004). As a specific community of interest, older people can participate through older people's forums, Better Government for Older People, an Older People's Assembly, older people's networks, user panels, day centre or care home user groups, older persons' services planning groups or forums, and project-specific working groups (Carter and Beresford 2000 and Barnes and Bennett-Emslie 1997). At a practical level, this includes being able to influence services and policy development through setting agendas and participation at meetings, co-producing services with other stakeholders, being involved in the design and commissioning of research and services, involvement in inspections through the experts by experience programme and volunteering in the community.

At a more individual level, participation means being able to influence decisions about care and support during the process of assessment and care planning, and being able to organise personal budgets.

Older people's participation in research

Older people can participate in research at all its stages and directly shape and inform the enquiry. Examples of participative research, its findings and outputs, such as assessment frameworks and tools, are given below.

The following examples describe approaches that involve a broad cross section of older people. Unless specific mention is made of dementia, communication support needs and other specific conditions, the original sources do not always make it explicit that people with high support needs were included. There is also a lack of information concerning people over the age of 85.

Keys to a Good Life framework (Bowers *et* al 2009)

Funded by the Joseph Rowntree Foundation, this action research study presented older people's vision of what a 'good life' looks and feels like to them. The six keys are:

- personal identity and self-esteem
- meaningful relationships
- personal control and autonomy
- home and personal surroundings
- a meaningful daily and community life
- personalised support and care.

The Northampton Healthy Communities Collaborative

The Healthy Communities Collaborative is a partnership of the primary care trust, the borough council, social services, Care and Repair and Age Concern. It started as a small project that engaged local people to reduce the incidence of falls among older people in Northampton. The majority of the volunteers were older people. It has also

been active in other initiatives – all based on engaging and supporting local people to take control (Klee 2006).

SPRU research with older users of home care services

Researchers from SPRU explored how older users of home care would like to be consulted. Interestingly, individuals asked if they could speak directly with the senior manager of the service – with advance notice of the questions – instead of completing a questionnaire. They felt they would be able to exert more influence this way, by getting managers to experience firsthand what their everyday realities were (Patmore *et al* 2009).

Joseph Rowntree Foundation research with older people)

This research programme was defined by older people and focused on their experiences, service responses and involvement in setting agendas. Its findings were presented in 'Older people shaping policy and practice' – a report that draws together 18 research projects about issues that older people have raised as central to their lives. The report highlighted that the practice of involving older people in issues relating to their lives is still at an early stage, and the need for clearer and better standards on involvement. The projects included information, advice and advocacy, older people's own definitions of quality, the needs of black and minority ethnic older people and issues relating to involving older people (JRF 2004).

New Dynamics of Ageing Research Programme – Rural ageing (in progress 2012)
(www.newdynamics.group.shef.ac.uk/rural-ageing)

This study focuses on the quality of life of older people in rural areas by analysing the degree of their involvement in their communities, leisure patterns and cultural interests. It will also explore the barriers and opportunities for the participation of older people and their attitudes to the countryside as a social, cultural and environmental space.

Some participative research specifically considers older people with high support needs

The Better Life Programme (2009–2013) – Joseph Rowntree Foundation (JRF)
(www.jrf.org.uk/work/work area/better-life)

This five-year programme focuses on how to promote quality of life for the growing number of older people with high support needs in the UK. JRF has commissioned a range of work to inform the development of policy and practice that can help older people with high support needs irrespective of where they live. The programme is focused on developing best practice in care homes and housing with care schemes, as well as considering alternative approaches. Significantly, the programme aims to strengthen and listen to the voices of older people with high support needs and their carers. It challenges the service-led approach, and instead advocates a rights-based approach that promotes older people as equal citizens who are part of the solution. Much of the research referred to in this report has drawn from this initiative.

South East Regional Initiative (SERI)
(Granville *et al* 2011)

The South East Regional Initiative (SERI) was designed to demonstrate and measure the effectiveness of investing in independent living for older people with high support

needs following the launch of the Independent Living Strategy in 2008. Funded by the Office for Disability Issues (ODI), and working with three local authorities, this work focused on increasing the voice, choice and control of older people living in care homes and those living at home and at risk of moving into care. It used the Keys to a Good Life' Framework (Bowers *et al* 2009) mentioned earlier in this report. Six core findings emerged from the fieldwork.

1. Living a normal life – This finding links in particular to personal identity, personal authority and control, and having a meaningful life – three of the six 'keys to a good life' identified in earlier research. Older people with high support needs wanted the opportunity to 'live a normal life'. This included the value of having contact with peers and with people from other age groups, being able to handle and use money – which is often not possible when living in a care home, and finding ways to stay physically fit.

2. Maintaining an individual identity – The unique experiences and life histories that have shaped older people's lives affect how they respond to their current circumstances. This was central to people retaining their personal identity and autonomy, having a voice, and exercising choice and control in their lives.

3. Belonging – Older people need to belong to meaningful personal networks, have interests and activities outside their homes, and be a part of family and community life. This also links to meaningful relationships, one of the Keys to a Good Life framework. For people living in their own homes, the presence of informal support networks was significant in helping them remain in their own home. Networks were also important to care home residents, particularly those in areas nearest to their home.

4. Aspirations and hopes for the future – Some participants had very clear hopes and aspirations for their current and future lives, which covered a wide spectrum of interests, activities and relationships. Many people had aspirations that they did not expect to see fulfilled.

5. Permission and power – The question was raised of who holds the balance of power in relationships with or involving older people with high support needs. This highlights the insecurity and uncertainty of many people's situations, including not knowing what the rules are, or who makes the rules when living in a group situation. For example, in the context of care homes, people were not sure when and if they could go into the garden, and if and how they could invite someone to lunch. Similar feelings were shared, although less frequently, by those living at home.

6. Choice and control over finances – Choice and control over personal finances was a significant concern for those living in care homes as well as for those living in their own homes. Their experiences were varied. Some care home residents were in total control of their finances, challenging myths about older people with high support needs being unable to manage or control their own finances. All those interviewed who were living at home had access to money or funds for their own personal expenditure even if they did not directly manage them, in contrast to the experiences of participants living in care homes.

Some participative research specifically considers particular populations of older people with high support needs.

Assessing quality of life

The assessment of quality of life for people with dementia is complex, but it does not mean that individuals – including those with more severe dementia – are not able to communicate what matters to them. Alzheimer's Society research (2010) draws on the views and experience of people with dementia and highlights 10 key QOL indicators:

1. relationships
2. environment
3. physical health
4. sense of humour
5. independence
6. ability to communicate
7. sense of personal identity
8. ability or opportunity to engage in activities
9. ability to practise faith or religion
10. experience of stigma.

The research also indicates that there is often a discrepancy between the views of the person with dementia and their carers in terms of what quality of life means for that person.

Involve People with Dementia in Planning and Developing Services

Funded by the Department of Health (DH), this project produced a service development guide. It covers issues around involving people with dementia in service planning and development as well as a wide range of approaches that have been used. It also covers staffing issues that agencies need to address (*Cantley et* al 2005).

Dementia Care Mapping (DCM)
(www.positiveaboutdementia.co.uk)

Based on the philosophy of person-centred care, this is an observational tool for practice development and is based on the perspective of the person with dementia. It is used in settings such as care homes, hospitals and day care. The process involves briefing staff and users about DCM in the area to be mapped, observing a number of people with dementia over a period of time, recording information about their experience of care, analysing and interpreting the data and then feeding it back to staff. The data is then used to provide a more responsive and person-centred service to the older person.

Resources

This section sets out resources available to support co-production work in social care. It includes assessment tools that are the fruit of co-production research and development work, designed and tested with people who use services. It gives information on practice and service development undertaken in co-production and it also provides details of co-production networks and forums.

Tools

CARE profiles (Combined Assessment of Residential Environments)

The CARE profiles practice tool is an approach to the improvement of quality care homes for older people. It is designed to gather the perspectives of residents, relatives and staff who are all part of the collective in creating a positive home environment. It identifies areas for change based on these experiences. However, further development of the tool is necessary so that the views of cognitively impaired residents can be incorporated into the assessment process (Faulkner and Davies 2006).

Short Observation Framework for Inspection (SOFI) tool
(www.brad.ac.uk/health/dementia/dcm/sofi)

This is an observational tool for inspection and regulation. The tool uses a methodology to understand the quality of the experiences of people who use services who are unable to communicate because of cognitive or communication impairments. SOFI helps the assessor to understand whether people who use services are receiving good quality care appropriate to their individual needs. Importantly, the views and experiences of people who use services are central to the tool.

The Sheltered Care Environment Scale (SCES)

The SCES is designed to evaluate the social atmosphere of a care facility. It measures the extent to which these environments are cohesive, supportive and fostering independence, conflict and resident influence. The resident influence dimension measures the degree to which residents can influence the rules and policies of the facility and are free from restrictive regulations The SCES is based on participants' assessment of their environment (Lemke and Moos 1987).

The 360 Standard Framework
(www.360fwd.com)

The 360 Standard Framework (Care Homes) for excellence in person-centred care is the first outcome-based, quality improvement and practice development framework to deliver and maintain a person-centred culture. It improves business performance, occupancy and retention and involves residents, staff and relatives. Underpinning all service and practice standards, it goes beyond Essential Standards into the resident experience and provides evidence for public confidence as well as improving business efficiency

Football reminiscence project
(www.scotcip.org.uk/football)

This project uses football as a medium to engage with men who have been diagnosed with dementia. The key role of football historians, who are passionate about their subject, is critical. Participants produce a pack, which is theirs to keep and is a potentially useful resource for staff working with them. People with dementia receive the full attention of a volunteer who involves the older person in reminiscence work through the medium of football. Not only does the football theme stimulate memories and communication, but also links to other related memories

Life story

Life story work is not new to dementia care and the benefits are increasingly being recognised. For care staff it is a valuable tool in developing engagement with those with dementia. Its benefits include enabling care staff to understand the person behind the story and enabling their voice to be heard – verbally and non-verbally (McKeown *et al* 2010). Life story tools and techniques such as journals, story boards and memory boxes are enjoyable for all who use them. A life story approach allows the individual to map their past – where they have lived, their jobs, hobbies, family, the food they enjoy and other information specific to their life. It provides a context and focus for engagement with care home staff and family members.

Talking Mats

Talking Mats is a low-tech communication framework involving sets of symbols. It is an established communication tool, which uses a mat with pictures and symbols attached as the basis for communication. Talking Mats can help people reach a decision by providing a structure where information is presented in small chunks supported by symbols. It gives people time and space to think about and process information and say what they feel in a visual way that can be easily recorded (**www.talkingmats.com**).

Reminiscence therapy

Similar to life history, reminiscence therapy is a biographical intervention that involves either group reminiscence work or the use of stimuli such as music or pictures. It is designed to provide ways for people with dementia to express their needs through reminiscence. The Alzheimer's Society publication *Memories are made of this* gives a valuable starting point for those wishing to understand and apply the technique as part of a care strategy.

CIRCA (computer interactive reminiscence and conversation aid)
(www.computing.dundee.ac.uk/projects/circa)

Reminiscence therapy is important for people with dementia but the work may often be led and controlled by the carer. The CIRCA system helps people with dementia by presenting carefully selected audio and video which can be played via a touch screen to 'unlock' memories. It is a livelier and more engaging form of joint reminiscence activity than is possible with a paper scrapbook. CIRCA lets the individual take control by choosing clips that may trigger some memory and conversation. It is based on something called hypermedia – linked content that works like internet hyperlinks. It uses carefully chosen media as memory aids and prompts instead.

The Readiness Check Tool for independent living
(http://independentlivingresource.cpa.org.uk/IndependentLivingAndOlderPeopleReadine
ssCheck.pdf)

The Readiness Check for independent living can help authorities determine their capacity and plan how to deploy local resources to improve the life chances of older people with high support needs. It is based on the six key principles of independent living with older people:

1. increase voice
2. ensure equal access
3. enable choice and control
4. enable participation
5. join it up strategically
6. promote a new way of thinking

Practice development through co-production

There are several examples of co-production between local authorities, other stakeholders and older people to shape local services.

Age Concern (now Age UK) Bromley service model

(www.ageuk.org.uk/bromleyandgreenwich/our-services/support-planning-and-brokerage/)

In 2007 Bromley Council commissioned Age Concern Bromley to develop a service model to provide a support planning and brokerage service to older people who were self-funders. The services developed include:

- providing information, advice and guidance
- developing support plans
- advocacy
- coordinating support.

The service is person-centred and co-produced with older people and the wider community through Age Concern Bromley's network of Community Volunteers Time Bank (CVTB) members.

(www.ageuk.org.uk/bromleyandgreenwich/our-services/support-planning-and-brokerage)

Hertfordshire's Local Involvement Network
(www.hertfordshirelink.org.uk/Home/Howwevehelped/LINkgroups/Workinggroups/Older
People.aspx**)**

In this network older people are involved in a continuous process of dialogue about issues including transport, education and leisure.

Manchester Valuing Older People (VOP)
(www.manchester.gov.uk/info/500099/valuing_older_people/3428/valuing_older_people
_vop)

In 2003 Manchester City Council, NHS Manchester and community and voluntary organisations launched *Valuing Older People*. This partnership initiative aims to improve life for Manchester's older residents and involves them alongside a number of different services, organisations and agencies. Its work includes looking at age friendly neighbourhoods and tackling loneliness. As some individuals feel intimidated by formal meetings and are more concerned with local issues rather than city-wide ones, some parts of the city have a local Valuing Older People network, which brings together various groups – including older people – to help address local concerns through collective action.

Dorset Partnership for Older People Project (POPP)
(www.dorsetforyou.com/popp)

Dorset POPP puts older people at the heart of a county-wide partnership to improve older people's services. It also aims to help maintain independence and quality of life through the development of responsive, person-centred local services and activities. The programme has engaged extensively with older people, and is able to support and develop other initiatives including those in health and social care. Older people also conduct the evaluation programme that assesses the impact of services in the Dorset POPP.

The Dorset Age Partnership

This is a network of representatives from various older people's forums and groups, and strategic leads and lead officers from Dorset County Council, the primary care trust, the district councils, police, fire and rescue services and voluntary organisations. It is the theme group for the Dorset Strategic Partnership but has been designed as a partnership body where older people are in the majority, and is always chaired by an older person. It has district/locality groups – also with majority older people involvement – which influence its strategy.

The Dorset Age Partnership is significant in influencing Dorset-wide strategies. These include the development of an Extra Care Housing strategy for Dorset, where plans are reviewed to take account of older people's needs. An example of successfully influencing an outcome was the rejection of a planning application from a major care provider on the basis that their proposed new scheme was too large and would not support personalised services or independent living (NDTi and Helen Sanderson Associates 2009).

Quality of Life Partnership in Newcastle

Newcastle's Quality of Life Partnership was established in 2004, bringing together Age Concern Newcastle, the Elders Council, Newcastle Healthy City and Newcastle City Council. In 2008, support from the Joseph Rowntree Foundation helped the Quality of Life Partnership begin a programme of work to develop information, advice and advocacy for older people to address gaps in provision. Older people – including BME elders and the housebound – have helped to set priorities. Instead of creating projects

and new services, the focus has been on ways of working and how existing systems can be made more 'older person friendly', efficient, and effective (Horton 2009).

Brighton and Hove Lay Assessors
(www.bh-impetus.org/pensioner_action)

This group visit older people to ask about their experience of day-to-day support including their home care packages. Information about what is working and what is not gets fed back to the provider agencies and the local council. The group are volunteers recruited from – and co-ordinated by – the Brighton 60+ Action Group, who have a good relationship with the council and are funded by their Adult Services Social Care Department.

Networks and practice initiatives

Giving Us a Voice
(givingusavoice.org.uk)

The Association for Real Change (ARC), British Institute for Learning Disabilities (BILD) and Mencap have written a national Charter for Inclusion for people with learning disabilities and their families from ethnic minority communities. The team worked to involve people with learning disabilities and their carers in regional meetings to tell local policy makers what they need and expect from services. There is clear evidence that services are not currently reaching these communities. They are often excluded from taking part locally by lack of contact and language difficulties. *Giving us a Voice* tackles this problem by challenging service providers and commissioners to sign up to the Charter for Inclusion. The regional meetings hoped to encourage future participation by local communities in service planning.

A Quality Network review
(**www.bild.org.uk/tqn/tqn_about.htm**)

A 'Quality Network' supports its members to review services for people with learning disabilities. It builds a culture of continuous learning, quality improvement and better outcomes for people who use services. A review is based on 10 outcomes, which have been developed from evidence gathered from inspections and regulation by the British Institute of Learning Disabilities in association with people who use services, family carers and support staff. The 10 outcomes measure:

1. choices
2. being involved in decisions
3. being respected
4. involvement in everyday activities
5. friendships and relationships
6. involved in local community
7. opportunity to work
8. family's views being heard
9. safety from bullying and abuse
10. staying healthy.

A Life in the Community

This organisation has established good practice in daytime opportunities for people with high support needs. It was designed as an action research project to help individuals and their families find active and positive roles in their communities. The information was shared with their partners to help improve services for people with learning disabilities. (Swift and Mattingly 2009)

The Older LGBT Network
(www.ageuk.org.uk/cymru/professional-resources/older-lesbian-gay-bisexual-and-transgender-lgbt-network)

The Older LGBT Network is a network of older lesbian, gay, bisexual and transgender people. They work in partnership with other organisations – including those with a wider remit – as well as campaigning and meeting regularly. The network allows people to make their voices heard and to share information, ideas and best practice.

Gay and Grey
(www.somerset.gov.uk/irj/go/km/docs/CouncilDocuments/SCC/Documents/Resources/Equality%20Documents/Gay_and_Grey_report.pdf)

This is a joint initiative between a voluntary agency (Help and Care), a university and older people and their carers on the south coast of England – with the fifth largest lesbian and gay population in UK towns. Amongst its work, it has highlighted some of the problems experienced by lesbian and gay older people in the context of residential- and community-based care, including discrimination in services (*Ward et* al 2008).

Involving and consulting BME elders

Involving and consulting BME elders: proud to speak up is a guide produced by Age Concern East Midlands (Zahno et al 2009) with practical suggestions to involve BME older people so that they can participate in public life. It also includes advice and good practice so that current and future services will be more accessible and appropriate (Zahno *et al* 2009).

Meri Yaadain project
(www.meriyaadain.co.uk)

The absence of a word for 'dementia' in the main Indian languages results in treatment that is not appropriate to people with dementia. This project uses local radio, literature, talks and outreach work in an effective way to engage with people with dementia and their carers.

BME Elders' Forum
(www.futureyears.org.uk/issues/bme_elders)

The BME Elders Forum is currently made up of organisations mainly from London and the Midlands. Its aim is to become a national forum by developing membership in all regions, to represent the interests of as wide a range of black and minority ethnic elders as possible. One example is the Leicester Age Concern BME elders' forum, which unites over 40 groups from the BME community through involvement, bringing together the community and the development of resources.

My home life
(http://myhomelife.org.uk)

This is an initiative that involves residents, relatives and others within the care home community. It is led by the care home sector together with Age UK, City University and the Joseph Rowntree Foundation. It aims to improve the quality of life of those who are living, dying, visiting and working in care homes for older people, and its vision is based on a review of best practice undertaken by the National Care Homes Research and Development Forum (NCHR&D Forum). It is underpinned by the concept of relationship-centred care and the Senses Framework. A subsequent programme of ongoing research and development identified eight best practice themes, which collectively form a vision for care homes in the 21st century:

- managing transitions

- managing identity

- creating community

- shared decision making

- improved health and healthcare

- supporting good end of life

- keeping workforce fit for purpose

- promoting a positive culture (NCHR&D Forum 2007).

Enriched Opportunities Programme
(ihsc.worc.ac.uk/dementia/enriched)

The Enriched Opportunities Programme (EOP) was developed by ExtraCare Charitable Trust, and the Association for Dementia Studies at the University of Worcester as a means of ensuring that people living with dementia in care homes and extra-care housing can continue to enjoy a good quality of life. EOP brings together best practice in a structured, systematic and proactive way. Key aspects of the programme include a specialist staff role – the EOP Locksmith – to unlock or promote the social inclusion and quality of life of residents with high support needs.

Older Women's Co-housing group
(www.owch.org.uk)

Co-housing is often described as recreating 'friendly neighbourhoods' or creating 'intentional neighbourhoods' (Manthorp 2010).

The idea of co-housing is to bring together individuals and families in communities of shared interests, while allowing people to enjoy their own self-contained accommodation and privacy. One of its principles is that communities are established and managed by their members for mutual benefit – so groups of individuals work collectively to solve housing problems for themselves with support if necessary (Burke 2010). There are ten co-housing communities in the UK, some going as far back as the late 60s. An example is the Older Women's Co-housing group – a group of older women in north London who are currently living separately and alone. They are

planning a co-housing project that they will all move in to once it is completed. In the meantime they are getting to know each other socially.

Fife User Panels

Age Concern Scotland initiated Fife User Panels to enable older people over 70 who are unable to leave their homes without assistance to get together. The aim is for them to develop a collective voice to express their needs and experiences and be involved in the planning of local services. Learning from each other is an important aspect of panel membership. This includes obtaining information about services and learning how others dealt with their problems (Barnes and Bennett 1997a).

Greater London Forum for Older People
(www.greaterlondonforum.org)

The Greater London Forum for Older People supports London forums and groups through advice on governance, marketing, publicity, fundraising, recruiting and training new members, and influencing the local Council, NHS, MPs, MEPs and statutory bodies. Local borough forums include individuals, representatives of older people's organisations and other bodies. The main concern of a forum is to represent its own views to the local authorities, MPs, MEPs, Greater London Authority members, councillors and statutory and voluntary agencies. The forums advocate and campaign on national and regional issues that affect older people. A borough forum provides older people with the opportunity to participate in borough strategic frameworks and policies, and decisions about local services.

Scottish Dementia Working Group
(www.sdwg.org.uk)

The Scottish Dementia Working Group (SDWG) is an independent group run by people with dementia. Membership is only open to people with dementia. The group campaigns to improve services for people with dementia and to improve attitudes towards them.

Elders Council of Newcastle
(www.elderscouncil.org.uk)

The Elders Council evolved from an organisation called The Older People's Network and is Newcastle's older people's forum. It has been active since 2001. In June 2003 the Elders Council published a strategy called *The Way Ahead*, which looked at how older people's quality of life in Newcastle could be improved. This strategy was subsequently endorsed and funded by Newcastle City Council.

Speaking up for our Age
(www.ageuk.org.uk/get-involved/older-peoples-forums)

Speaking up for our Age is an Age UK programme that supports independent local forums by providing practical support, start-up development grants, conferences and training sessions across the country, as well as a regular newsletter to keep forums connected. Age UK has also produced a booklet to share good practice on the effective engagement of older people on the design and delivery of local services. It includes a wide range of case studies on engagement initiatives.

Older People's Advocacy Alliance
(www.opaal.org.uk)

OPAAL is a registered charity with 142 member groups. It aims to provide the strategic lead in the development of independent advocacy for older people – which includes promoting independent advocacy with older people as a right – and developing standards. It works with partners including advocacy schemes and alliances across the UK, community development agencies, and national and regional bodies. Its priorities include incorporating the involvement of older people within the organisation and developing its links with minority ethnic communities.

Shaping Our Lives networking website
(www.shapingourlives.org.uk)

This website provides support for service user organisations, service users and others interested in supporting the development of local user involvement. User-controlled organisations can voice their views and concerns. It also provides information and support about service user involvement at a national level and enables groups to link to other user-controlled groups.

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Co-production and participation: Older people with high support needs

This report gives a summary of a review of literature and a small-scale survey of good practice on the participation and co-production of older people with high support needs.

This is a key issue for all involved in social care from policy makers through to frontline practitioners but the report will be of particular interest to

- commissioners of social and health care services,
- people working in housing provision
- service users and others developing the co-production/participation agenda in care provision and service development.