Office for Disability Issues
HM Government

The 'SERI' Story

Increasing the Voice, Choice and Control of Older People with High Support Needs in the South East of England

Outcomes, Findings and Lessons

May 2011

National Development Team for Inclusion
and the Centre for Policy on Ageing

NDTi
National Development Team for inclusion

Centre for Policy on Ageing
CPA
New attitudes to old age..

Acknowledgements

Many people have been involved in the design, delivery, analysis and writing up of the South East Regional Initiative to produce this 'SERI story' for sharing with a wide audience to influence change. We would like to thank and acknowledge the contributions and commitments of the following people:

Everyone involved in the work that took place in Portsmouth, Oxfordshire and West Sussex: older people with high support needs who participated in the workstreams, "voice mapping" work, and the qualitative research; the local leads who gave so much of their time and energy to guide and enable SERI to take root locally; members of the local steering and workstream groups who showed commitment and passion for improving the lives of and services for local people. We would also like to thank the South East England Forum on Ageing for their initial enthusiasm and support to make the project happen in the south east.

Members of the national Project Board and Analytical Advisory Group came from varied backgrounds and busy jobs with competing demands on their time; we have valued their contributions, advice and support over the last two years.

Pen Mendonca, Jo Seddon and Maggie Beat provided expert advice, design and development support on the voice mapping, peer coaching/mentoring and community inclusion aspects of this work.

Members of NDTi's change management and qualitative research teams who have focused their hearts and minds on this work over the last two years, and who are committed to taking the priorities for change forward.

The Centre for Policy on Ageing who have been involved throughout and who developed the policy and best practice analysis that accompanies this report.

SERI could not have happened without the foresight, and investment of time and resources, from the Office for Disability Issues. The ODI project team members have encouraged, cajoled, supported and challenged the work throughout in order to ensure that the work is robust and of wider relevance beyond the participating sites.

Contents

Foreword

Working together to ensure that the voice of older people with high support needs is heard not only brings benefits to individuals but also to family members, communities and society as a whole. It also helps commissioners and organisations providing local services design support that meets the aspirations as well as needs of older people, giving them true choice and control over their lives.

I am pleased, therefore, to present the outcomes, findings and lessons from the South East Regional Initiative (SERI). This evidence is relevant to anyone involved in developing, informing or providing support and services to/for older people across all sectors - public, private, or voluntary & community (civil society organisations).

As this report shows, there are a number of low cost but significant changes that can be made to improve and embed independent living for older people living in or at risk of moving into care homes. It is clear from the findings that older people want to remain active citizens and continue to be involved in family and community life, wherever they live. The authorities participating in the SERI developed a range of ways of achieving this goal, this report shares their experiences and practical strategies for making this happen.

The accompanying web-based Resource Pack and Qualitative Research Findings Paper form part of this body of clear evidence about what works for older people with high support needs in different settings.

I would like to thank everyone who has contributed to the success of this project. I hope that the findings in this report will make a positive contribution to increasing the awareness and understanding of older people's needs and aspirations, and addressing the barriers they face in exercising choice and control over their lives.

Tim Cooper, Director, Office for Disability Issues.

Summary

This report presents the findings and conclusions of a two year change management and research programme on increasing the voice, choice and control of older people with high support needs that took place in the South East region of England.

Background

The South East Regional Initiative (SERI) was designed as a demonstration project to develop and measure the impact of imaginative approaches in promoting independent living for older people living in care homes, and older people at risk of moving into care. Its focus, therefore, was not just about health and social care but the widest possible range of options and opportunities for support. Three local authorities (Portsmouth, Oxfordshire and West Sussex) and their partners participated in this programme, and worked together to achieve positive changes in the lives of older people with high support needs. Their lessons and stories are shared in this report.

The outcomes and lessons from this work have significance for a number of Government spending departments, specifically the Departments of Health, Communities and Local Government, Transport, Work and Pensions, the Cabinet Office, the Office for Civil Society, the Office for Disability Issues and the Treasury. It is also relevant to other government departments such as Department for Environment, Food and Rural Affairs (Defra), given the significance of ageing populations in rural areas, especially in the over 85 age group. A key focus that will be of major interest to all of these audiences is the learning derived from developing low cost, high impact support that enhance people's lives and improves local service delivery. No new monies were used to achieve the changes shared in this report.

More locally, the South East Joint Improvement Partnership (JIP) and Association of Adult Directors of Social Services (ADASS) have embarked on an ambitious programme to support local areas in the process of transformation and improving personalisation of

services to local communities. It is hoped that this report will provide further evidence to encourage a range of initiatives designed to increase the voice, choice and control of older people throughout the South East.

The South East Regional Initiative (SERI)

The SERI programme comprised three key elements, involving specific activities and work programmes within and across the participating sites:

i. Change management support to partners and communities in Portsmouth, Oxfordshire and West Sussex. This element involved the design and provision of support to develop and embed options that promote independent living. The initiative covered the spectrum of support that older people need to lead their lives, regardless of their eligibility for state funded support and care. Details about specific priorities addressed within and across the sites are provided in Chapter 2.

ii. A qualitative research study designed to answer the key question:

"What is different [as a result of the above] for the two target populations of older people with high support needs within and across each site, during the course of the Regional Initiative?"

iii. Quantitative data collection and analysis to capture impacts and develop an outcomes framework for independent living that can be used by authorities to assess the return on their local investments. This involved the development of a quantitative data collection and analysis grid, in order to contribute to the evidence base of "what works" and investigate the impact of independent living on the two target populations.

Key Features of Change

Six key features stand out from this work, which we believe need to be addressed in order to achieve change at a local level. These are presented below as a series of steps or actions that can be taken to embed independent living with and for local older people with high support needs. They are intended to be read and addressed sequentially, rather than in 'order of priority'; each of the six features is equally important and requires the same amount of attention as all the others. However, addressing some key features before others will help ensure there is a 'local readiness' for change.

1. Increasing choice and control improves the lives and life chances of older people with high support needs

Increasing voice, choice and control across all aspects of life[1] makes a huge difference not just to older people's quality of life but to their health and wellbeing more generally[2]. We have learnt that establishing this connection is critical for creating the right conditions for the following 5 features.

This change is not down to a radical re-shaping of health and social care services and/or interventions. It is the result of a radical change in the nature of the relationship between public services and older people with high support needs and local communities; and changes to the nature of support that is available within and

[1] Housing, transport, participation in community life, personal finances, access to goods and services, and the nature of individual support required

[2] Hurstfield, J. et al (2007). The costs and benefits of independent living. Office for Disability Issues (via: http://odi.dwp.gov.uk/docs/res/il/costs-benefits-summary.pdf); Heywood, F. (2001). Money well spent: the effectiveness and value of housing adaptations. The Policy Press; Dunning, J. (January 2010) Early intervention schemes lead to better health: Bradford and Tameside show the way for NHS-council partnerships Community Care online, via: http://www.communitycare.co.uk/Articles/2010/01/29/113673/older-people-early-intervention-schemes-lead-to-better-health.htm

across those services regardless of where people live, their impairment or condition, or their eligibility for certain services.

The most important change of all is a commitment from all public services to work together and with local older people with high support needs to increase the choice and control that they and others have over any assistance they need to lead their daily life.

There are three specific messages to emphasise from SERI:

- Adopting person centred approaches is a simple and cost effective way of increasing choice and control, especially for people who need a lot of support in their lives and those whose voices are seldom heard (see also Feature 2)
- These approaches and other examples shared in this report do not have to cost additional money but will require changes in how resources are allocated and used. Increasing personal choice and control improves decisions, avoids the need for more expensive resources, is a rewarding experience for staff, and ensures older people access the right support or service at the right time for them.
- This is about all public services, and so requires strong partnerships and a pooling of resources across spending departments and sectors in order to achieve this re-allocation of resources and priorities. This agenda is not just the responsibility of adult social care, nor of local authorities, nor of the NHS. Working with older people to increase their choice and control is a collective responsibility which requires collective action and unified leadership (see Feature 5).

2. Increasing voice and visibility is the first step towards greater choice and control for older people with high support needs

Increased choice and control cannot happen if people have no voice with which to express their views, preferences and opinions. The voice of older people with high support needs is still too quiet and/or absent at all levels of decision making and influence. In

addition, there is a very low set of expectations among the current generation of older people with regard to their rights, and what is possible and available as alternatives to traditional forms of support.

We found that the SERI sites were still at the “consultation” rung of the empowerment / participation ladder in the early stages of this work. Moving towards coproduction as a way of amplifying people’s voice and increasing their influence is therefore a crucial feature of independent living, but involves significant shifts in order for those who currently have the greatest voice and influence over decision making to release and share this power (see Factor 4) and to develop a different relationship with older people, service users, communities, colleagues and partners.

3. Greater participation and involvement in family and community life is a key priority for older people with high support needs

Older people with high support needs want to and can be contributors and place shapers themselves. They do not want to be and should not be regarded as passive recipients who drain the public purse. Older people with high support needs involved in SERI have stressed how much they want to be treated as equals, and to carry on participating in family, community and civic life - in many instances doing the things they have done all their lives - including routine household chores, gardening, going out to the shops and being in charge of their own destinies with support if they need it. They certainly do not want to be 'cared for', kept busy or occupied by others. Many residential and day care settings provide people with opportunities to take part in additional, organised activities. We have found that these organised activities are not welcomed by everyone and tend to dominate, to the extent that they over-ride support to do the things that matter to older people individually.

Understanding people's individual histories and personal experiences is crucially important and easily achieved as a result of adopting tried and tested approaches for delivering person centred services and support. This requires a new focus and way of thinking about current developments (such as those associated with the vision for a Big Society[3]) to ensure that those who are marginalised or excluded, find it difficult to get their voices heard, who live alone or whose networks are shrinking are equally engaged and can contribute.

4. Changing the balance of power is a necessary part of increasing older people's voice, choice and control

Choice and control is about a fundamental shift in power between public services, professionals, local communities, service users

[3] http://thebigsociety.co.uk/what-is-big-society/

and carers. Across all of the sites and elements of SERI, we found a dominant belief that independent living is about extending existing service based solutions (i.e. it's an access issue) and that professionals either know or must find out the answers to the problems /priorities identified. This is a barrier to coproduction (see Feature 2) and to transforming the way that services are designed and delivered, leading to workload problems for already overloaded staff.

As well as adopting coproduction, there is a need to foster and encourage greater cross fertilisation between communities, teams, services and organisations. The current imbalance of power is felt not just by older people with high support needs but family members, staff and some specific groups (e.g. people living with severe and fluctuating mental health problems; black and minority ethnic communities; travelling communities; homeless people; etc).

5. A bold vision for change needs bold leadership to make it happen

The scale and scope of change involved in applying the learning from SERI and increasing the voice, choice and control of older people is significant, wide reaching and challenging but achievable – as the examples, case studies and stories in this report illustrate (see Chapter 3).

Whilst independent living is about lives, not just services, making it happen with and for older people with high support needs will require changes within services as well as among older people, families and local communities. It requires a strong shift in policy away from a focus on "long term care" and "needs" towards citizenship, rights and equality. Leadership across the public service system is important in achieving this change, as is leadership within teams and organisations delivering specific services. The leadership of older people with high support needs is equally important in creating the right conditions for change.

6. Outcomes matter: measure what's important to older people with high support needs

Outcome measures and associated data monitoring processes to demonstrate things are changing and how, and to track returns on investments, need to be developed and integrated into future change programmes from the start.

These outcome measures need to closely reflect what matters to older people about their lives and support; and to link these changes to wider impacts for services and local systems of support. We found that it is not the norm for staff involved in delivering services (and some of those commissioning services) to have access to 'outcome data', to share this data or to engage in discussions or exercises that facilitate a shared understanding about what "their" data is telling them.

An additional challenge is that where developments and services have been coproduced, this necessarily means that outcome indicators, and data to measure them, will relate to much broader issues and changes outside the direct control of those commissioning and delivering more traditional services. Accepting this feature of independent living and working with it requires systemic as well as cultural and attitudinal change - regarding what information is collected from where and how this is analysed, interpreted and used by whom.

There are clear connections between this Factor and leadership at all levels, including the need to clarify and widen ownership of different data sources; and develop the right conditions whereby staff working at different levels are confident and incentivised to collect, analyse and share data that links to changes in people's lives.

Priorities for Local and National Action

As a result of this learning, six priorities for action are also set out in the main body of the report (see Chapter 4) comprising actions – mostly local and some national – that will help to improve the life chances of older people with high support needs.

i. Develop a shared vision for improving the life chances of older people with high support needs, including:

- Agreeing "what success looks like" across the whole of older people's lives – and therefore capturing the contributions of all public services (and beyond) for achieving this vision
- Securing commitment from all partners, commissioners, providers and communities/groups to develop a citizenship focus and ethos in order to shift attitudes and adopt positive strategies both for ageing well[4] and increasing the voice, choice and control of those who need a lot of support in their lives.

ii. Co-produce services and plans with older people with high support needs, including:

- Committing to increasing the voice and influence of older people with a diversity of experiences and need for support – in shaping what services are available and how they are delivered, and resourced
- Supporting the development of user and peer led groups/networks in facilitating a stronger, collective voice of older people with high support needs to be heard
- Creating opportunities for older people with high support needs to engage in local developments, and in shaping their own support, based on their priorities and circumstances.

[4] http://www.idea.gov.uk/idk/core/page.do?pageId=20344655

iii. Take a whole system, whole community approach to join up networks, services and resources, including:

- Working together across local services and communities to pool and/or otherwise share resources (monies, time, people, knowledge, skills and ideas)
- Using the practical tools developed through SERI to a) assess the relative strengths and weaknesses of current partnership arrangements (using the Partnership Readiness Framework[5]) and; b) assess local readiness for independent living with and for older people with high support need (using the Independent Living and Older People Readiness Check[6])

iv. Adopt person centred approaches to drive through change and focus on older people's hopes, aspirations and priorities, including:

- Reviewing local practice, experience and outcomes (to identify what's working and not working); and stimulating change through providing development support to maintain and spread what works in enabling older people with high support needs to have a good life.
- Working with older people who are currently engaged in local developments as well as enabling participation from those whose voices are currently not heard, to ensure that local decisions (e.g. about where to start and what needs to change) are driven by coproduced priorities and plans.
- Engaging all public services, not just health and social care, in adopting person centred approaches, e.g. by promoting community inclusion as the overarching goal of person centred approaches, as well as developing joint/pooled training and development resources and opportunities

[5] Greig R. and Poxton, R. (2001) From joint commissioning to partnership working – will the new policy framework make a difference? Managing Community Care. 9(4): 32-38

[6] http://www.independentlivingresource.org.uk/IndependentLivingAndOlderPeopleReadinessCheck.pdf

- Working in partnership to identify, agree and communicate the first steps and early signs of change together, and keeping people on track as they develop new ways of working and wider opportunities for support.

v. Invest in and develop strong system, community and peer leadership to deliver the fundamental changes involved, including:

- Supporting the development and profile of strong leaders at every level and across all aspects of commissioning and providing support that enables older people to lead their daily lives.
- Developing and disseminating a greater range of personal stories and images of possibility to demonstrate what can be achieved through increasing the voice, choice and control of older people with high support needs
- Enabling, encouraging and incentivising the widespread adoption of positive practices and attitudes, so that older people are no longer seen as passive recipients or only vulnerable and in need of care
- Creating and promoting opportunities to develop and use the leadership skills and capacities of far greater numbers of older people with a diversity of experience, background and support needs.

vi. Develop meaningful outcome measures for use by ‘data-confident and competent’ staff, including:

- Outcome indicators that can be used at a local (ongoing) and national (annual) basis to measure progress in improving the life chances of older people with high support needs.
- Clarity about who or what the outcome/change is for; the consequent outcomes/changes for services and the system; and the changes it is hoped that the system outcomes will bring about for individuals and whole populations.

- Guidance on national and local data collection and analysis to achieve less focus on volume measures (and trend analysis based on volume measures) and a greater focus on outcomes for individuals and the system as a whole.
- Learning resources that enable diverse partners and stakeholders develop a shared understanding about what to measure and collect across the local system.
- Better understanding about local populations of older people with high support needs across the range of existing and emerging commissioners and providers. For example, promoting the use of 'POPPI' - Projecting Older People Population Information - designed to give councils easy access to forecasts of the numbers and characteristics of older people in their locality[7]. Recent work on establishing the trends and characteristics of older people with high support needs is also relevant here, but would benefit from further disaggregation to determine what this means at a local level[8].

[7] http://www.dhcarenetworks.org.uk/csed/dfAndCapacityPlanning/poppi/
[8] Falkingham, J., Evandrou, M., McGowan, T., Bell, D. And Bowes, A. Demographic issues, projections and trends: older people with high support needs in the UK. JRF Programme Paper: A Better Life. October 2010

1. Chapter 1: Introduction and background

This report presents the findings and conclusions of a two year change management and research programme on increasing the voice, choice and control of older people with high support needs that took place in the South East region of England.
Chapter 1 sets out the background, rationale, aims, intended outcomes and impacts for different stakeholders involved.

1.1 Background to the South East Regional Initiative

The South East Regional Initiative (SERI) was funded by the Office for Disability Issues (ODI, www.odi.gov.uk) to work with three local authority areas - Portsmouth, Oxfordshire and West Sussex - to develop options and embed broader opportunities for independent living for older people with high support needs at a local level. Two target populations were identified as the main focus for this work: older people currently living in care homes, and older people living at home and at risk of moving into care.

SERI was one of two commitments that focused on improving the life chances of older people in the Independent Living Strategy[9], which states:

Older disabled people must have the same options and opportunities for independent living as anyone else and the Strategy contains a number of commitments which will help achieve this goal.

The second commitment involved the development of a web based toolkit for senior professionals working across public services,

[9] Independent Living Strategy: a cross government strategy about independent living for disabled people. Office for Disability Issues. February 2008

containing information, advice and practical strategies for promoting independent living for all older people. This toolkit can be accessed at www.indepedendentlivingresource.org.uk.

1.2 Purpose and aims of SERI

SERI was designed as a demonstration project and took place in one English Region – the South East - to initiate, develop and measure the impact of imaginative approaches in increasing the voice, choice and control of older people living in care homes, and older people at risk of moving into care. The specific objectives of SERI were to:

- Capture and assess the development, implementation and effectiveness of innovative approaches and interventions to improve access to early and ongoing support that promotes independent living;
- Examine the experiences and personal outcomes arising from increased voice, choice and control for older people living in care homes, as well as those living at home or in supported accommodation to avoid a move into care.

These developments have significance for a range of audiences:

- Older people and their families
- People leading and working in Local Authority departments (not just in adult social care, but across all services and teams)
- Third sector and broader civil society organisations providing a wide range of amenities, goods and services to local communities
- NHS organisations, including specialist as well as mainstream health services and teams.

The work also has significance for a number of Government spending departments, specifically the Departments of Health, Communities and Local Government, Transport, Work and Pensions, the Cabinet Office, the Office for Civil Society, the Office for Disability Issues, and the Treasury. It is also relevant to other government departments such as Defra, given the significance of

ageing populations in rural areas, especially in the over 85 age group[10].

The provision, funding and outcomes of intensive support for older people are shared concerns and priority areas for the audiences identified above, as they prepare for an increasingly diverse and ageing population and the impact this will have on local communities, goods and services. At the same time, public resources and spending are reducing, with subsequent cuts to local services and/or tighter criteria for accessing them.

Many authorities still commission and provide services from clearly delineated services, departments and budgets with little or no joint commissioning taking place across health, social care, housing, transport, neighbourhood regeneration, community safety, police, fire and rescue. Practical lessons, therefore, about how to develop strong partnerships and pool scarce resources were felt to be of relevance to all and each of these audiences.

The evidence-base that informs policy within and across these departments is complex, multi-faceted and often fragmented[11]. The South East Regional Initiative was therefore designed to work across these policy and spending departments and audiences, to build a reliable and practical evidence base about “what works for whom, in which circumstances, and why” in enabling older people with high support needs to access and experience independent living.

[10] Chapman, Sherry Ann and Peace, Sheila (2008). Rurality and ageing well: 'a long time here'. In: Keating, Norah ed. Rural Ageing: A good place to grow old? Bristol, UK: The Policy Press, pp. 21–32.
[11] Mayhew, L. (2005). Active Ageing in the UK – Issues, barriers, policy directions Innovation: Journal of Social Sciences Research. Volume 18, Issue 4 (pp455-477); http://www.independentlivingresource.org.uk/ilrop-tools-resources.html

1.3 Scope and intended outcomes

It was envisaged that the outcomes and benefits of SERI would be experienced by individuals and their families, and staff working at all levels in a range of services, teams and agencies:

- Individuals and families would experience greater choice and control over a wide range of options and opportunities, including locally based support to enable a return home from hospital or other settings. They would have a much greater say over day to day life and routines, including decisions affecting their support and opportunities for participation.
- Local Authorities and their partners would enable more older people with intensive support needs to live at home or in accommodation of their choosing; and be assisted to reach locally agreed as well as (then) national targets (e.g. participation and satisfaction with neighbourhood and home; older people supported at home; reduced care home and hospital admissions; older people accessing and using a personal budget).
- Local systems and communities would be supported to stimulate a more diverse range of support options, with a reduced need for expensive health and social care services and care home places over time. They would develop stronger relationships and new partnerships, sharing resources, costs and risks associated with investments in these areas.
- All partners would develop greater knowledge and understanding about the full spectrum of possibilities for support, and awareness about local communities and their needs and aspirations.

The South East region was involved in this programme for two main reasons. Firstly, the region has a significant ageing population (see Appendix 1 for detailed information). Secondly, a number of interested bodies and authorities from the South East – including the Government Office of the South East, the Department of Health South East (DHSE), and the South East England Forum

on Ageing - expressed an interest in participating in the work, to support the three local authority areas involved across the range of public services and partners/communities.

There was a clear connection between this Initiative and other national and regional programmes, including local developments associated with the personalisation agenda, extra care housing developments, and NHS reforms including investment in reablement and intermediate care services. The focus on the two target populations from a 'whole life' perspective was seen as especially valuable for generating new knowledge and learning.

Portsmouth, Oxfordshire and West Sussex - the three participating authority areas - represented a 'good spread' across the region in terms of overall numbers and projected increases of older people, and wider demographic and socio-economic characteristics (ethnicity, wealth/deprivation, urban-rural, county-unitary authorities etc). They had all previously been involved in an initial scoping study commissioned by ODI, to establish the focus and design of this work[12].

The work therefore operated at a local and regional level, as well as including mechanisms (a high profile national Project Board and cross site Action Learning Events) to draw out lessons for wider application across the country.

1.4 Policy context and background to SERI

In addition to building the case for change and demonstrating what works and how to achieve this, SERI formed part of a complex web of national, regional and local initiatives taking place between 2008 and 2010, including:

- The transformation of adult social care (the Personalisation agenda);

[12] http://odi.dwp.gov.uk/docs/wor/ind/scoping-study.pdf

- The development of strategies to promote and indicators to measure the impact of whole system working across all public services (Total Place);
- The development and design of new housing aids, adaptations and equipment alongside a wider range of housing options with support (Lifetime Homes, Lifetime Neighbourhoods; investment and development of extra care housing options; and the implementation of the First Stop Advice services coordinated by EAC;
- The Better Life Programme at the Joseph Rowntree Foundation aimed at exploring broader options and opportunities for ensuring older people with high support needs live a good life;
- Programmes designed to increase the voice and influence of diverse groups (the Unheard Voices Programme at the Joseph Rowntree Foundation; the coproduction network hosted by Nesta);
- The network of demonstrator sites and pilots supporting the implementation of the National Dementia Strategy;
- The Trailblazer sites, which are testing the Right to Control, in order to enable disabled people to have choice and control over the support they receive which will help them achieve their full potential;
- The Dilnot Commission on the future funding of care and support
- The South East England Health Strategy (2008) which set out a very broad policy context and policy objectives designed to improve the health and wellbeing in Later Life across the region.
- The Ageing Well programme supporting local authorities to improve local services for older people and develop positive strategies for an ageing population.

In order to make sense of this context, the Centre for Policy on Ageing undertook a targeted review of the literature on national and policy trends covering the period November 2008 to October 2010. This analysis: a) identified and mapped key frameworks relevant to the work of the SERI sites and teams supporting or

working with them; b) tracked key changes in the social, political and professional contexts within which local developments have been taking place; and c) identified examples of best practice relevant to the work of the SERI sites, highlighting "evidence" of what works in increasing the voice, choice and control of older people with high support needs. The full policy analysis paper is available at www.cpa.org.uk.

The remainder of this section highlights key points pertinent to understanding the SERI context, and also provide insights into how the programme developed during this period.

SERI was undertaken against the background of a worldwide financial crisis, a UK general election and a new UK coalition government, and the most widespread cuts in departmental and local public services in a generation. The period spanning 2008-2010 was therefore one of great flux, and this sense of shifting sands was strongly reflected in what we heard and found at an individual and local level in the SERI sites.

As the programme came to an end in late 2010, numerous questions about funding and ideological positions on what should be funded and invested in for the future were being raised and debated within the 3 SERI sites. There was a prevailing sense that, whilst older people with high support needs had become a priority for the authorities involved, this population still had a low profile and visibility elsewhere[13].

The greatest challenge identified from the policy analysis is the lack of effective implementation and consistent adoption of "best practice", particularly across the whole spectrum of public services, for the two target populations at the heart of SERI – older people living in care homes and those at risk of a move into care. It was this lack of focus on ensuring that older people with high support needs have equal access to the same options and opportunities

[13] http://odi.dwp.gov.uk/docs/wor/ind/scoping-study.pdf; Independent Living Strategy: a cross government strategy about independent living for disabled people. Office for Disability Issues. February 2008

for independent living that led to SERI being developed. Effective implementation and methods for achieving sustainable change that are low cost and high impact are key concerns in this report.

1.5 Independent Living and Older People with High Support Needs

The terms and focus on “older people with high support needs” and “independent living” have caused much debate and some degree of confusion throughout the SERI programme. This section explains why, and offers a rationale for continued focused attention both on the issues and the language that SERI participants (sites and communities) found useful.

1.5.1 What do we mean by ‘Independent living’?

The definition of ‘Independent living’ developed by disabled people (including older disabled people) is set out in the Independent Living Strategy[14]:

‘Independent living’ does not mean doing things for yourself or living on your own. Instead, it means:

- having choice and control over the assistance and/or equipment needed to go about your daily life;
- having equal access to housing, transport and mobility, health, employment and education and training opportunities.”

‘Support’ therefore refers to any aspect of life and the full range of public and commercial services (i.e. not just health and social care) available including housing, equipment, information and advice, and travel, learning and leisure - as Figure 1, also from the Independent Living Strategy, illustrates.

[14] Independent Living Strategy: a cross government strategy about independent living for disabled people [Chapter 1: Vision, aims and outcomes]. Office for Disability Issues. February 2008

Figure 1 - Independent Living Vision[15]

Independent Living Vision: All disabled people will have the same choice, control and freedom as every other citizen and any support is based on individuals' own choices and aspirations

- Greater choice and control over any assistance you need to go about your everyday life
- Access to housing, transport, health, social care, education, employment and other services and opportunities
- Participation in family, community and civic life

'Voice' is the first, essential, step in ensuring that anyone who needs support in their life is able to exercise choice and control. If you are not able to express yourself (e.g. because of verbal communications difficulties such as aphasia or advanced dementia[16]) and/or your opinions are not heard (e.g. because you are not involved in decision making), it is difficult to exercise choice and control over the things that matter to you. Actions and interventions that promote voice, as well as choice and control are therefore key features of independent living.

Four priorities for increasing the life chances of older disabled people, were identified during the Independent Living Review (that resulted in the Independent Living Strategy), which were addressed in part through the SERI programme. These priorities are:

a) The need for a deeper understanding of what an "ageing population" means, including specific characteristics and factors for different communities in different locations. There is currently a lack of understanding about who constitutes 'older disabled people' and a lack of association among older people with this term.

[15] Independent Living Strategy: a cross government strategy about independent living for disabled people. Office for Disability Issues. February 2008

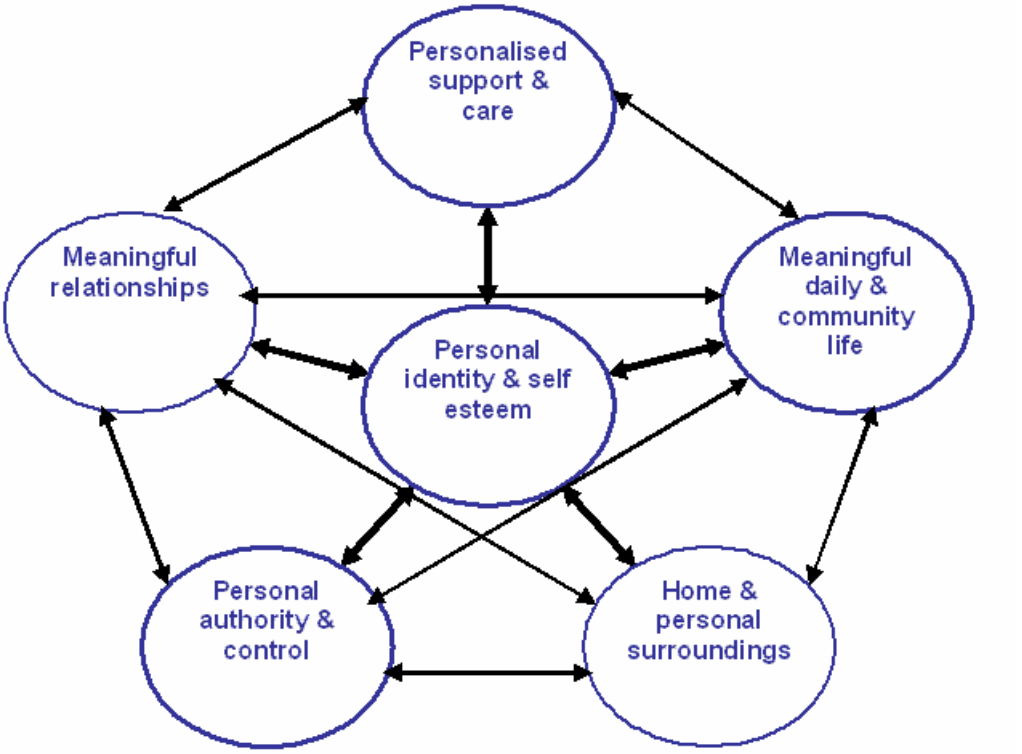
[16] Overcoming the obstacles to the improvement of dementia care: report of the Scottish Executive and Alzheimer Scotland Short Life Working Group (2004) Scottish Executive.

b) The need to make greater progress on joining up policies, plans and people across public services, and in particular beyond health and social care, so that support available to older people enables them to lead their lives
c) "Equal access" to a broader range of options and opportunities for independent living including self directed support and housing. Greater access to housing information, advice, and options is a particular priority.
d) The need to address ageist attitudes and assumptions at all levels - from policy formulation and implementation through to commissioning and delivery.

A separate research study into older people's vision for long term care (commissioned by Joseph Rowntree Foundation's Independent Living Committee)[17] led to the development of a framework for increasing the voice, choice and control of older people with high support needs.
This study worked with older people in four study sites living in care homes and extra care housing, to capture what's important to as well as what's important for older people in order to have choice and control over their support, in order to have a good life.

[17] Older People's Vision for Long Term Care . Bowers et al (2009), Joseph Rowntree Foundation

Figure 2, Keys to a good life framework, is the diagram which summarises the outcomes of that work.



This framework was as an important starting point for SERI and a central design feature of the qualitative research (see section 2.3). Along with the Vision for Independent Living referred to earlier, it was also used to explain and clarify the goals, direction and desired outcomes to partners and local stakeholders involved in each of the SERI sites.

1.5.2 Older people with high support needs

The Better Life programme hosted by the Joseph Rowntree Foundation[18] warns against using too rigid a definition when referring to 'older people with high support needs'.

[18] http://www.jrf.org.uk/work/workarea/better-life; Older people with high support needs: how can we empower them to enjoy a better life? Blood, I. 2010. Joseph Rowntree Foundation's Better Life Programme.

They emphasise the complexity and diversity of our ageing population and the range of circumstances, individual characteristics and needs that are influenced by a variety of factors:

“Both ‘older’ and ‘high’ are comparative and subjective and this begs the question of who decides: medical diagnosis, social care assessment, older people themselves or their families? Viewed from a social model of disability, an older person who is physically frail, has a chronic condition or multiple impairments, could have low support needs if they live in accessible housing with enabling technology, within a supportive community”

They use the following definition:

‘Older people of any age who need alot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years of age. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle etc. Some of the very oldest people may never come into this category.’ ”

The definition adopted by sites participating in SERI is:

“Older people who need alot of support in their everyday lives, regardless of age, condition, where they live or ability to pay for support”

It was emphasised from the start that this work was not strictly “age specific”, although the focus was on people over 65. It was also stressed that the work was not impairment specific, i.e. not led by diagnoses or conditions, although how these impact on life may well be important considerations for older people. We were keen within all elements of the work to engage and involve people living with dementia, both because of the consequences of projected increases in the numbers of people of all ages with dementia, and

because their voices are often not heard or facilitated in their own support or wider developments.

1.5.3 Understanding the target populations

There is evidence indicating that older people with high support needs are amongst those least likely to exercise choice and control over the support they receive; and that this support does not enable them to lead the lives they want to lead, including choice over where to live[19]:

- Older people who have significant support needs are often not identified as benefiting from preventative interventions and support that enhances their independence and wellbeing[20].
- Many people 'at risk' who could benefit from services are not receiving them. [21]
- Recent developments to improve services for older people have placed less emphasis on the mental health needs of older people, yet depression is one of the most prevalent conditions in later life, estimated to affect one million older people[22]
- People with dementia make up 64% of older people living in care homes and a quarter of those living in housing with care

[19] Bowers, H. et al (2009). Older people's vision for long term care Joseph Rowntree Foundation; Blood, I. (2010). Older people with high support needs: how can we empower them to enjoy a better life? Joseph Rowntree Foundation.

[20] ndependent Living Strategy: a cross government strategy about independent living for disabled people Office for Disability Issues. March 2008

[21] Wanless, D. et al (2006) Securing Good Care for Older People: taking a long term view. The King's Fund.

[22] A Sure Start to Later Life: ending inequalities for older people. A final Social Exclusion Unit Report (2006) Department for Communities and Local Government http://www.communities.gov.uk/publications/corporate/surestart; All things being equal: age equality in mental health care for older people in England. (2009) Mental Health Foundation.

schemes[23]. There are key gaps in the evidence comparing different models of support and housing with care and their cost effectiveness for people at different stages of dementia[24].

- Independent living 'mechanisms' and approaches such as person centred planning, self directed support, circles of support, personal budgets, brokerage and user led organisations have been less widely applied and/or less easily accessed by older people with intensive support needs, although this trend is starting to improve in relation to personal budgets[25].

It was agreed a multi-faceted approach was needed to address these issues, to ensure local services and systems are better geared to meeting the needs and aspirations of older people with high support needs living in care homes and those at risk of moving into care.

This report, the accompanying Findings Paper (focusing on the qualitative research) and web based resource pack, have been written to bring this experience and evidence together in one place - to pool and share the knowledge, lessons, outcomes and messages from SERI.

[23] Blood, I. (2010). Older people with high support needs: how can we empower them to enjoy a better life? Joseph Rowntree Foundation; Percival, J. (2010). Attitudes to frailty, disability and end-of-life in housing with care

[24] Garwood, S (2010). A better life for older people with high support needs in housing with care

[25] Personal budgets and older people: making it happen (2009). Department of Health

2. Chapter 2: Telling the SERI story - what, where and how

This Chapter provides background information on the SERI programme elements and participating sites, and sets out the context for the six features of change, case studies and examples that follow in Chapter 3.

2.1 Introducing SERI

The SERI programme involved three key elements involving specific activities and work programmes within and across the participating sites:

i. Change management support to partners and communities in Portsmouth, Oxfordshire and West Sussex. This element involved the design and provision of support to the SERI sites to develop and embed options that promote independent living. The initiative covered the spectrum of support that older people need to lead their lives, regardless of their eligibility for state funded support and care. Further details are provided in Section 2.2.

ii. A qualitative research study. This element of the programme used the Keys to a Good Life Framework (referred to earlier) to design robust research tools and fieldwork methods to answer the key question:

“What is different [as a result of the above] for the two target populations of older people with high support needs within and across each site, during the course of the Regional Initiative?” See Section 2.3 for further details.

iii. Quantitative data collection and analysis. This element of the work was undertaken in partnership with the 3 sites, to capture impacts and develop an outcomes framework for

independent living that can be used by authorities to assess the return on their local investments. This evolving element involved NDTi and ODI analysts working with the 3 sites, the change management team, the qualitative research team and the project's analytical advisory group to develop a quantitative data collection and analysis grid, in order to contribute to the evidence base of "what works" and investigate the impact of independent living on the two target populations. See Section 2.4 for details.

The change management support and qualitative research was delivered by the Older People and Ageing Programme at the National Development Team for Inclusion (NDTi, www.ndti.org.uk) working in partnership with the 3 sites, and the Centre for Policy on Ageing (CPA, www.cpa.org.uk). NDTi also worked with ODI and the Project Board to develop the framework for quantitative data collection and analysis. The timeline and key deliverables across all three elements of SERI, covering the period November 2008 - March 2011, are set out in Appendix 2.

2.2 Introducing the SERI sites and their areas of focus

Figure 3 introduces the SERI sites and their priorities for increasing the voice, choice and control of older people with high support needs, which then formed the focus of the change management support and activities.

Interactive 'design days' were held to bring a diverse range of partners and stakeholders together, including older people with high support needs, in each site to identify and agree these priorities - also known as areas of focus, and/or 'workstreams'. A key message at this stage was that in discussing local priorities, it was important to think about the whole spectrum of current and possible future support available across all public services as well as local goods, facilities and amenities, including (but not exclusively):

- A wide range of housing related advice, support and equipment
- A broad base of community support including social networks and opportunities for participation
- Accessible transport and help to get around
- Access to information, advice and support on a range of issues
- Access to peer support and user led organisations/ networks
- Access to a wide range of leisure and learning opportunities
- A focus on changing lives and improving services through personalised services and support in health and social care.

Examples of the processes and tools used to explore and agree local priorities are available through www.ndti.org.uk

Figure 3: The SERI sites and their focus areas

Site: Portsmouth

Area of Focus / Workstreams:
A densely populated urban, unitary authority on the south coast with a population of 188,500 (2004 mid-year estimates) which is projected to grow to 204,500 by 2026

- Adopting person centred approaches to increase choice & control of older people living in 1 care home
- Developing a neighbourhood focus to independent living, to enable older people with high support needs living in one neighbourhood to stay connected, contributing, and living at home in their community.

Site: Oxfordshire

Area of Focus / Workstreams:
The most rural and least densely populated of all South East county areas, with about half of the population living in areas made up of less than 10,000 people.

- Adopting person centred approaches to increase choice & control of older people living in 7 care homes (2 of which are supported by 'SERI').
- Developing & delivering tailored information for older people living with dementia to increase their choice & control in living at home.
- Designing transport options to enable older people with high support needs to participate in community life, maintain networks & reduce social isolation, especially in rural areas.

Site: West Sussex

Area of Focus / Workstreams:
A mixed urban and rural county on the south coast, with a large and increasing population of people aged over 65.

- Adopting person centred approaches to increase choice & control of older people living in 2 care homes.

- Increasing the voice and influence of older people with high support needs in the planning and development of a new enablement service.
- Increasing the voice of older people with high support needs in their discharge from hospital, improving their access to different support options.

2.3 Design and methodology of the qualitative research

The qualitative research programme aimed to find out what is different for the two target populations of older people with high support needs within and across each site, over the course of SERI. This involved two main areas of enquiry, or primary research questions:

1. What are the experiences and feelings of voice, choice and control like now amongst these two populations; and what are the key influences on these experiences and feelings?

2. What is changing or has changed as a result of the mechanisms, interventions, options and opportunities for increasing the voice, choice and control of older people with high support needs? What has helped or hindered?

Sixteen subsidiary research questions were identified from examining these lines of enquiry. Research activities to answer these questions were carried out in 5 phases spanning the period from November 2008 to December 2010. Detailed information about the methodology and the findings from the qualitative research is available in the accompanying Findings Paper, and summarised in Appendix 3.

The research team demonstrated a model of co-production in research, with members including two older people, one of whom has high support needs, two senior fieldwork researchers and one researcher focusing on co-ordinating fieldwork administration from

an office base. The rich mix of ages, knowledge, experience and perspectives generated valuable insights and enabled important learning to emerge about the lives of people whose voices are seldom heard in research.

Ninety nine (99) research interventions were undertaken between April 2009 and September 2010, with 63 individual older people with high support needs, plus observational work and discussions with consultees (e.g. family carers, friends and spouses). Approximately 50% of this sample related to the care home workstreams and 50% to the community workstreams. One third of the sample had a confirmed diagnosis of dementia. This body of evidence illustrates the 'data rich' nature of this study, the results of which form a Data Bank that can be used for further, focused analyses and interrogations if required.

A major lesson from this element is that the process of research can be a change mechanism in itself. The combination of the change management activities and the qualitative research contributed to changes on the ground. Future initiatives combining different elements of development support, research and evaluation will need to reflect this inter-dependency in the design and methods used.

The research demonstrated that the two target populations can have a voice in and through research activities. This is particularly relevant in view of the many gatekeepers and obstacles that were put in the way of the team reaching and engaging diverse older people with high support needs in this study. The fact that the research team involved older people as peer researchers and took people's engagement, views and contributions seriously, impacted on them and their gatekeepers.

2.4 The design and approach of the quantitative data analysis

NDTi and ODI analysts worked with the 3 sites (through local leads and steering groups) to support them to collect as much management information relating to their areas of focus and the two target populations as possible (for example by drawing on their JSNAs and targeted studies). No simple data set or single measure adequately captures or reflects the range of interventions involved, and the timescales involved were too short and the sample size too small to involve statistically reliable methods. However, it was agreed that existing, easily accessible quantitative measures could be used in combination with information from the other two elements to provide useful information and important lessons about developing practical and meaningful measures for independent living.

NDTi analysts built an Evidence Grid consisting of each site's areas of focus, outcome indicators and agreed sources of data; and common outcome indicators relating to the care home and increasing voice workstreams. A site specific and cross-site analysis of returned data was undertaken during November and December 2010, based on site data collected until the end of October 2010 (until the end of December for two workstreams). The evidence grid is shown in summary table form in Appendix 4.

Important lessons and experiences from undertaking this element of SERI are outlined below:

- In each site and in relation to each workstream, it is clear that a plethora of data exists which is being collected for various purposes

- The majority of local data that is readily available is predominantly 'input data' (e.g. how many staff deliver and how many people admitted or accessed which service/support); there is some output data (e.g. numbers of staff trained, numbers of people with a support plan); and a general lack of outcome information/data (e.g. improved health and wellbeing, reduced levels of depression, reduced staff turnover)

- Comments received from those providing data imply a lack of familiarity, confidence and understanding about “outcomes” and the measures and data that indicate whether (and how) these have been achieved

- Some good examples of initial attempts to collect outcome information were evident across the sites, including: brokerage outcome data in Oxfordshire, inclusion web data from Portsmouth and the use of indicator data in West Sussex. Each of these approaches could be built upon to strengthen the collection of individual and local service outcome information

- Sites were wary of sharing some information and data, e.g. relating to costs. When probed this was mainly because they themselves do not have this information, rather than a resistance to sharing sensitive data

- There is a variety of secondary data and profiling information available for organisations to use to interrogate local services and deepen their understanding of older people with high support needs. Examples include the West Midlands Public Health Observatory information profiles[26]; and the POPPI population profiles and projections[27]. None of the sites referred to this data or were using this to better understand the two target populations in their area (despite advice and offers of support to enable this to happen).

[26] http://www.wmpho.org.uk/olderpeopleprofiles/default.aspx
[27] http://www.poppi.org.uk/

3. Chapter 3: Key Features of Change

This Chapter shares six key features of change that need to be addressed in order to increase the voice, choice and control of older people with high support needs at a local level. These Features are drawn from the cross cutting analysis of research findings, change management outcomes and quantitative data, i.e. all elements of the SERI Programme.

The outcomes and achievements of the different workstreams taken forward by the sites are also included in this Chapter, as illustrative case studies which can be used to inform change in different areas.

The six features are summarised in Figure 4 below.

Figure 4: Six Key Features of Change

1. Increasing choice and control improves lives and the life chances of older people with high support needs
2. Increasing voice and visibility is the first step towards greater choice and control
3. Greater participation and involvement in family and community life is a key priority for older people with high support needs
4. Changing the balance of power is a necessary part of increasing older peoples' voice, choice and control
5. A bold vision needs bold leadership to make it happen
6. Outcomes matter: measure what's important to older people with high support needs

These Features are presented as a series of steps or actions that can be taken to embed independent living with and for local older people with high support needs. They are intended to be read and addressed sequentially, rather than in 'order of priority'; each of the six features is equally important and requires the same amount of

attention as all the others. However, addressing some key features before others will help ensure there is a ‘local readiness’ for change.

3.1 Increasing choice and control improves the lives and life chances of older people with high support needs

Increasing voice, choice and control across all aspects of older people’s lives (in relation to housing, transport, participation in community life, finances, access to goods and services and the nature of individual support required) makes a huge difference not just to quality of life but to their health and wellbeing more generally.

This change is not the result of improving health and social care services and/or interventions. It is the result of changing the relationship between public services and older people with high support needs, and with local communities; and of changing the nature of support that is available within and across those services, regardless of where people live, their impairment or condition, or their eligibility for certain kinds of support. The key priority for change is a commitment from all public services to work together and with local older people with high support needs to increase the choice and control that they and others have over any assistance they need to lead their daily life.

There are three specific messages to emphasise in relation to this Feature:

- The first is that adopting person centred approaches is a simple and cost effective way of increasing choice and control, especially for people who need alot of support in their lives, and those whose voices are seldom heard (see Feature 2)
- The second is that this does not have to cost additional money but will require changes in how that money is

allocated and used. Increasing personal choice and control can improve decisions and avoid the need for more expensive resources (e.g. associated with hospital admissions and care home placements), and ensure people access the right support or service at the right time (e.g. early on when less costly interventions have greater effect).

- The third is that this is about all public services, and so requires strong partnerships and a pooling of resources across spending departments. It is not just the responsibility of adult social care, nor of local authorities, nor of the NHS. Working with older people to increase their choice and control is a collective responsibility which requires collective action.

Case study: Adopting Person Centred Approaches and Strengthening Community Relationships in Care Homes

Fred's story

Fred Jones is 66 years and moved to a care home specialising in the care of people with dementia in December 2009. He moved there from hospital, following treatment for a head injury after falling in the street.

Fred had an alcohol dependency problem and had not been looking after himself. When he was admitted to hospital he was physically frail, had a poor short term memory and was diagnosed with dementia. Fred had been made redundant from working as a plumber in the Dockyard a few years previously, since when he had lived on his own in a local flat. He was good friends with his (former) work colleagues and neighbours. His work, however, had been his life and when he lost his job he found it difficult to find another one. He became depressed and started to drink heavily.

As Fred recovered from his injury he became restless at not being able to freely access the outside world. He continually referred to

the care home as “The Hotel” and his flat as ‘Home’. The home was requested to apply for a Deprivation of Liberty to enable them to keep him in the building legally, and he was also prescribed medication to help staff manage the situation.

Through the SERI work, staff spent a lot of time talking to Fred and getting to know him. They listened to his life story, which helped to explain his routines; he still got up at 7.30am and would become distressed if he thought he would be late for work or had left his car outside with the keys in it. Through these conversations, he began to remember more recent events, and as his memory improved his frustration increased at not being allowed to leave the building. Staff working with Fred called a meeting to discuss his future. A plan was developed to support him to become increasingly independent within the home, e.g. helping with cooking, cleaning, laundry and money management. They agreed some ground rules meaning he could leave the building and return safely. Each time Fred returned from his trips out, he was much happier. He learned and remembered the codes to the doors and eventually came and went as he pleased.

A strong bond developed between Fred and those who had listened and planned with him. A new social worker became part of these discussions and following a lengthy process, Fred went home to live back at his flat.

We have learnt that by listening to the person and giving them opportunities to use the skills they have and advocating on their behalf, it is possible to make huge improvements to someone’s life.

Adopting and embedding person centred approaches towards supporting older people living in care homes to have a good life - doing the things that matter most to them, maintaining their relationships and developing new ones - was a common priority across all SERI sites. A cross site training and development programme for staff, older people living in care homes and family members. This programme combined interventions that promote

community inclusion with person centred approaches (PCA) using person centred thinking and planning tools that have been shown to be effective with older people with a range of support needs and living arrangements[28].

Key aspects of the PCA and Inclusion Programme

- A one day introductory programme, delivered twice in each site for people from participating homes, covering the principles, practices and outcomes associated with person centred approaches and the use of person centred thinking skills and tools.
- Two follow up days per site providing more in-depth learning and for participants to share what they had changed, how and with whom, including stories and examples to explore with colleagues
- For one home per site, a one day community mapping/inclusion module covering the principles and practices of community and social inclusion; a “traffic lights” exercise to identify current approaches and levels of engagement with local communities; activities, relationships and supports that enable strong community relationships to develop; an introduction to the inclusion web[29]; and a community mapping exercise supporting staff to spend time in the local area where each home was based to initiate relationships with “mainstream” facilities and services.

‘PCA’ and brokerage go hand in hand in Oxfordshire

The participating homes in Oxfordshire integrated the use of person centred approaches and community inclusion with the development of independent support brokers in partnership with Age UK Oxfordshire (a model which was also later adapted for the

[28] These tools and a resource pack are available as free downloads on www.practicalitiesandpossibilities.com

[29] http://www.ndti.org.uk/publications/ndti-publications/inclusion-web-resource-pack/

targeted transport information and advice line)[30]. This pilot scheme resulted in 52 residents accessing a much wider range of opportunities and pursuing interests outside their care home environment on an individual basis, with consequent improvements in health, reduced medication levels, reduced staff sickness and happier residents and staff. The council has now invested in 15 new brokerage posts that will focus solely on working with and supporting older people living in care homes across Oxfordshire.

Achievements

PCA and Inclusion development support was provided to 110 staff in 5 care homes across the 3 sites, and 20 older people and family members.

This combined approach of linking person centred approaches with a deeper understanding of community inclusion resulted in improved lives and community connections for 170 older people resident in these homes, who are finding ways of living their lives with support to do the things that they identify are important to them.

For older people living in the participating homes, being empowered to speak up about their preferences and having people bothered to get to them know as a unique and valued human being was profoundly life changing. It is reported that people are happier, levels of depression and low mood have reduced, challenging behaviour has reduced, health and wellbeing have improved, and some people have returned home.

Staff participating in the programme reported that they know how to do things differently to deliver person centred support that makes everyday life meaningful for older people living in care homes. Staff sickness levels and turnover have reduced, morale has improved, and routine workloads have changed to reflect a more individualised approach to providing support.

[30] http://www.ageconcernoxon.org.uk/brokerage/about.html

Mr R's story

Mr R is a very sociable man who has travelled extensively throughout his personal and working life. He is proud of his career working for Calor Gas, where he held a senior position. He has become very forgetful and often doesn't remember that he has moved to live in XXX [name of care home]; he is convinced this is a temporary arrangement. Mr R's passion is sailing. He used to own a large yacht, and would sail every chance he got.
In finding out more about Mr R's history and wishes, it was identified that he would love to go sailing again. He spoke fondly of his sailing days and the staff working with him felt that this signified a liberating and independent time, where he was in control of his boat and his life. The broker researched the nearest possible venue, and made contact with Oxford Sailing Club at Farmoor Reservoir, who were enthusiastic about supporting him to take up sailing again, accompanying him to ensure his safety.

The first trip to Farmoor was organised within 3 weeks of this conversation, and Mr R now goes sailing approximately every 2 months.

"The look on Mr R face when he got into the boat told the story. He was in his element, in control of the boat, his increased feeling of independence made a difference in his overall mood and he now has something to look forward to and something that brings back fond memories".

This experience has opened up a whole new venue and enjoyment for many other residents; Farmoor reservoir has now developed 'sail-ability' which means other people with high support needs can go out on the water with a friend, family, or staff member, and enjoy the feeling of liberation and freedom on the water.

Each of the three sites are rolling out the new ways of working, skills and knowledge gained to other local care homes, for example:

- the West Sussex Care Training Consortium have embraced the PCA/community inclusion model and are encouraging its roll out across the county;
- Oxfordshire County Council and existing independent providers have agreed to roll out the PCA/community inclusion and brokerage scheme out to all care homes in the county;
- Portsmouth are cascading the approach across all care homes in the city.

The 'PCA and Inclusion Programme' has been further developed following the experiences of the SERI sites, and is outlined in the Independent Living and Older People resource pack available through www.ndti.org.uk.

Lessons

The underpinning philosophy of the PCA and Inclusion Programme is that seeing older people with high support needs as unique and valued human beings with gifts, talents and contributions is vital to supporting them well and doing a good job. Older people living in care homes are still most often regarded as someone with "complex needs" who may be "challenging" and /or difficult to engage and get to know. Staff and residents involved in this programme developed a shared understanding of older people's aspirations and histories, as well as their priorities for support.

Focusing on people's lives and goals means that outcomes for residents and families drive changes in practice, rather than service demands or resource constraints. These changes bring benefits for everyone involved: individual older people get to lead the life they want, and to feel valued and part of home, family and community life; families are more engaged and confident about how best to support their relative; staff also feel engaged, confident and empowered to support people on an individual basis with positive and tangible outcomes.

This shift illustrates the need and importance of local, strategic leaders in enabling such change programmes to be implemented; and of operational leaders (care home managers and owners) in embracing the programme, enabling staff to participate, and encouraging them to embed new ways of working

Treating this programme as an ongoing development process, rather than “one-off training”, is important for its effective implementation. The most cost effective way of organising and delivering this approach is as a series of ‘in situ’ coaching and mentoring sessions that are built into daily routines and practice. This avoids the need for staff cover, the hire of special venues, and enables observations of changes to routines, experiences and day to day support and opportunities.

Working in this way, and organising services around individuals’ needs and aspirations has implications for the inspection and registration of regulated services; and for commissioners and providers of intensive support services such as those found in care home and other settings to ensure these approaches become engrained in the culture, ethos and delivery of local services. They may also need support to understand how to change what they do and how in order to promote and incentivise more services to work in this way.

Pauline’s Story

Pauline is an outgoing woman who used to live in Spain and worked as a singer. Both her husband and son have died. She is diabetic and has previously struggled with alcohol difficulties. She chose to move to live in a care home as she felt she wasn’t coping well at home. Pauline’s keyworker (now the home’s Person Centred Support lead) met regularly with her, to get to know her and find out about her wishes and dreams. Pauline likes being out and about, not stuck indoors, and she loves swimming. Together they worked out how she could be supported to do these things, e.g. finding out about the local swimming pool’s opening hours, bus routes and taxi fares.

We discussed the best approach, which was that I would meet Pauline at the swimming pool and swim with her. Because Pauline is diabetic, we obtained a tracker for her so she can learn how to check her insulin levels. We also used the internet to identify other things going on locally that she could get involved with– e.g. Bingo, also on the bus route. Pauline enjoys shopping and now travels to a number of the local towns by bus using her pass. This is a very person centred approach that helped Pauline venture into the community with confidence. She now has choice and control over her day-to-day life, is able to go out whenever she chooses and generally feels fitter and more stimulated. She has grown in confidence and feels she has the best of both worlds – independence with security.

We have learnt to treat each person as an individual with their own unique life story. Spending time talking to people is invaluable and enables us to provide person-centred support. Undertaking this training has widened the opportunities available to residents as we now consider activities and opportunities available in the local community.

3.2 Increasing voice and visibility is the first step towards greater choice and control for older people with high support needs

Increased choice and control cannot happen if people have no voice with which to express their views, preferences and opinions. Previous work[31] and the early experiences of SERI sites[32] indicated that the voice of older people with high support needs is still too quiet and/or absent at all levels of decision making and influence. In addition, there is a very low set of expectations

[31] Bowers et al (2009) Older people' vision for long term care. Joseph Rowntree Foundation

[32] http://www.ndti.org.uk/publications/ndti-insights/insights-3-increasing-voice-choice-control-for-older-people-with-high-suppo

among this generation of older people with regard to their rights and to what is possible and available as alternatives to traditional forms of support.

The SERI sites have found a strong belief among partners and local stakeholders that independent living is about extending existing service based solutions (i.e. it's an access issue); and that professionals either know or must find out the answers to any problems /priorities identified. This is a barrier to coproduction with older people, and leads to workload problems for already overloaded staff. Moving towards coproduction as a way of amplifying people's voice and increasing their influence is therefore a crucial feature of independent living. This requires those who currently have power over decision making to give up and share this power, and to develop a different relationship with older people, service users, communities, colleagues and partners

Case Study: Targeted actions for increasing the voice and influence of older people with high support needs

A central aim of SERI was to increase the voice and influence of older people with high support needs. This common workstream included an extensive mapping exercise in each area, to capture existing arrangements and experiences in relation to the "voice" of older people with high support needs. This covered activities and arrangements aimed at increasing individual voice and influence (in terms of influencing people's own support); and those aimed at increasing the collective voice in terms of influencing local services and options available, including broader commissioning decisions and community developments.

Prior to SERI there was little evidence that older people with high support needs were engaged in local developments or existing opportunities for participation to inform decision making. This work was therefore starting from a very low base in terms of experience (of engaging, being engaged and working in partnership with older people with high support needs), expectation, confidence, knowledge and understanding about independent living.

Key Actions

Over 100 older people with high support needs were involved in 'voice mapping exercises' undertaken within and across the 3 sites.

Mapping older people's voice and influence

1. Mapping the current picture of voice and influence in the 3 sites started with initial discussions to engage local people, to raise awareness and clarify the aims and outcomes of this work.
2. Simple, desk based searches were carried out to plot existing mechanisms for local people, older people and older people with high support needs to have a voice and influence decisions.
3. A call for information was issued to groups identified, asking about their experience of these opportunities and what difference they make on the ground.
4. A series of informal discussions and meetings with people involved in these groups followed, focusing on those engaging or representing the SERI target populations.
5. The results of the above were pulled together with the help of a graphic facilitator[33], and a large wall map was designed for each site to share this information more widely.
6. A one day "voice mapping" event was held in each area to share this information and identify priority actions with participants (older people with high support needs and others involved in local developments).

[33] Graphic Facilitation is a technique using big pictures, illustrations, images and words to help large, diverse groups to come together and explore issues, ideas and options in order to reach decisions and take actions that achieve change.

Achievements

- 22 older people with high support needs became closely involved in the design and delivery of the SERI workstreams
- 16 older people participated in the mentoring and coaching sessions delivered to increase confidence, awareness and understanding about the concepts and practical examples of independent living – and to identify sustainable (and in two sites, new) mechanisms for continuing this work at a local level
- There are plans in place within each site to maintain and grow this work with these individual older people with high support needs working as local “voice champions” or local community leaders. For example:
    - 6 people are part of a new User Led Organisation in Oxfordshire;
    - 2 people in Portsmouth are involved in establishing a new Older People’s Forum that will be the voice of older people with high support needs in the city, and are now actively involved in wider local developments;
    - 8 people are setting up a dedicated group to build capacity and act as a strong, independent voice in West Sussex.
- An environment has been created where older people with high support needs feel heard and valued, and their priorities inform local developments.

A set of powerful findings from these discussions was produced and explored with a range of stakeholders and partners in each site. The main reason for doing this was to establish a strong case for change, and commitment to taking this work forward locally. These have wider resonance and relevance, and for that reason are summarised below.

Figure 4: The voice of older people with high support needs in local service and community developments

Invisibility and powerlessness

- Older people with high support needs often feel anxious about “speaking up” about their own support - especially if they are not well, live alone, or have few people in their life other than staff.
- Many feel ignored when they do raise their concerns, hopes and aspirations.
- Ageism in communities, services and the media has a powerfully negative, indirect and ‘creeping impact’ on older people’s lives, their prominence in other people’s lives, and their capacity to exercise choice and control.

Barriers to participation

- The lack of accessible public spaces and amenities, and inflexible transport and mobility solutions affect older people every day, including their participation in family, community and civic life.
- Not knowing what’s available, what’s possible or your rights and entitlements are common experiences for staff and families as well as for older people with high support needs.

Focus on building a collective voice and influence

- Older people with high support needs are not well engaged or involved in collective action and decision making. There is no apparent collective demand to be so, even though individually this is what people say they want
- Older people could have more control and greater influence if they came together and took action together to improve local services and amenities.

A cross site action plan for addressing these issues was agreed in order to maximise resources and impact in promoting and supporting a more influential voice for the two target populations. This action plan is provided in Figure 5, as we believe it could form a useful template for wider use at a local and national level.

Figure 5: How to increase the Voice and Influence of Older People with High Support Needs

1. Raise awareness of the benefits of increasing the voice and influence of older people with high support needs at an individual and collective level – better health, better decisions, better use of resources, improved life chances and quality of life, stronger family and community relations
2. Increase individual older people's influence and participation through person centred thinking and practical approaches such as circles of support and working with user led organisations to increase older people's profile amongst and work with disabled people of all ages
3. Increase older people's collective influence and participation, through supporting 2-3 older people with high support needs to become local leaders for change in each area; providing them with coaching and mentoring support to build their confidence, facilitate relationships with local decision makers, and identify ongoing mechanisms for keeping this work going.
4. Identify and share "what works" in achieving the above to ensure that older people's voices are embedded in local services and systems for the long term.

Lessons

A key feature of this work focused on skilling up older people with diverse experiences, backgrounds and support needs to increasingly take the lead in local developments. The change management teams supporting each site included an older person with expertise in working with older and disabled people to increase their participation and influence on decision making at these 3 levels. These personal relationships and networks proved to be an essential foundation for mobilising the collective voice of older people with high support needs in each area.

A key message from this work is that finding out what works and doesn't work for older people in terms of their own engagement and influence is crucial for ensuring the pace of change and nature of local developments work well for different communities of older people. Key characteristics that influence local partnership working with older people are highlighted in a guide to coproduction with older people which drew on the experiences of the SERI programme[34].

The following levers for change were identified by all those taking part in this element of SERI and in the qualitative research team, who also tapped into the direct voices and experiences of older people with high support needs.

Increasing voice, influence and participation – what works?

- Using people's individual stories to challenge assumptions and show what's possible, as well as what needs to change
- Using policy and legal drivers e.g. the single equality duty
- Older people showing the way and supporting other older people to engage, acting as role models, coaches and mentors
- Getting the right support in place to enable people to think about participating is crucial, before people can make plans and practical arrangements to do so
- Local and national elections (harnessing the 'grey vote') are potential mechanisms for reaching out to and engaging older people with high support needs at different points in their life
- Making links with other initiatives similarly designed to increase voice and inclusion in decision making is important. For example, these activities informed concurrent national and regional mapping exercises focusing on broader opportunities for older people to have an influential voice (through forums, advisory groups, partnership groups), and

[34] Personalisation: don't just do it – coproduce it and live it! A guide to coproduction with older people. Bowers et al, 2009. HSA Press.

which resulted in a new network of Regional Older People's Forums across the country[35].

3.3 Greater participation and involvement in family and community life is a key priority for older people with high support needs

Older people with high support needs want to and can be contributors and place shapers themselves. They do not want to be and should not be regarded as passive recipients who drain the public purse. Older people with high support needs involved in SERI have stressed how much they want to be treated as equals, and to carry on participating in family, community and civic life and in many instances doing the things they have done all their lives - including routine household chores, gardening, going out to the shops and being in charge of their own destinies with support to that if they need it. They certainly do not want to be 'cared for', kept busy or occupied by others. For example, many residential and day care settings provide people with opportunities to take part in additional, organised activities. We have found that these organised activities are not welcomed by everyone and tend to dominate, to the extent that they over-ride support to do the things that matter to older people individually.

Understanding people's individual histories and personal experiences is crucially important and easily achieved as a result of adopting tried and tested approaches for delivering person centred services and support. This requires a new focus and way of thinking about current developments (such as those associated with a Big Society) to ensure that those who are marginalised or excluded, find it difficult to get their voices heard, who live alone or whose networks are shrinking are equally engaged and can contribute.

[35] http://www.dwp.gov.uk/docs/uk-advisory-forum-190110-good-practice.pdf

Case Study: Developing Natural Networks of Support in Portsmouth

The need and opportunity to develop very locally based approaches for older people with high support needs living at home, was identified at the Design Day in Portsmouth. Early discussions with a range of partners highlighted the benefits of focusing this work in one neighbourhood in one ward of the city, to: combine strategic, community and individual level actions; improve local knowledge and understanding about older people living in this neighbourhood; strengthen community networks; and improve individual outcomes and experiences.

Drayton and Farlington was identified as an area with a high population of older people, including the “oldest old”, but with fewer admissions to hospital and care homes, where contact with adult social care was lower than other areas of the city. Beyond this high level profile, relatively little was known about older people with high support needs living there, or what works from their perspective. In addition to a desk based analysis of local demographic and epidemiological data, a one day “visioning event” was held in Drayton and Farlington, in order to engage local older people, community groups and other networks alongside agencies currently involved in the SERI programme in the city. It was agreed this needed to be inclusive and grounded in older people’s realities rather than services; and inform the practical actions that would follow.

Key Actions

A community based visioning event was held in a familiar community venue in the neighbourhood. This was attended by around 40 people including older people from the area and other parts of the city; disabled people and their organisations; local community groups and organisations; and representatives from health, social care and housing services.

A vision of independent living was developed with and for older people with high support needs living in Drayton & Farlington, outlined in Figure 6. A profound message from this event was that

older people felt they had lost their previously strong neighbourhood relationships and networks, and this was impacting on their lives.

Figure 6: A Vision of Independent Living in Drayton and Farlington

In 2030, Drayton & Farlington has....

- Good information and communication about local characteristics, needs, lifestyles and aspirations
- Good community spirit
- A village feel with a range of local facilities for all ages
- Inclusive, mixed housing that enables generations to mix
- A range of skills and experiences that are valued and used
- Neighbours who look out for each other, especially if someone is having difficulties.

A targeted programme of work to establish circles of support[36] for a small number of individuals living in one area of Drayton and Farlington was implemented. The aim was to learn from this in-depth work which would engage local voluntary organisations and community groups as well as staff from the council. It was also agreed that more needed to be done to strengthen and rebuild local networks in this area. A 'good neighbours' scheme was established by the Salvation Army to: connect individual older people with high support needs to existing local networks; exchange local information and 'know-how' to build inclusion where networks were missing; and promote the role and contribution of local voluntary organisations and groups.

Two members of staff from the council and three volunteers from local community groups and the Salvation Army were trained in person centred approaches associated with developing circles of

[36] A Circle of Support, sometimes called a Circle of Friends, is a group of people who meet together on a regular basis to help somebody achieve their goals and sometimes to help them use their personal budget to get the support they need in their life.

support with and for 9 older people with high support needs. This approach has since been adopted by the Salvation Army for further developing and delivering their befriending schemes across the city. The inclusion web[37] was used to capture a 'before and after' picture of inclusion and community connections with the individuals involved.

Achievements

Seven older people with high support needs were closely involved, with circles of support established to identify and meet their needs, goals and dreams. The two people who expressed an interest but didn't continue did go onto address specific issues or interests, for example:

- One woman accessed support from Silver Surfers so she could learn how to email family (grandchildren and her children) who live abroad
- One man came to a Circles information session, decided it wasn't for him but subsequently joined a men's cooking group that he found out about at this session.

Four inclusion webs were completed at two time points (T1 & T2) three months apart, between June and October 2010. The changes identified relating to the "people" and "places" in people's lives, highlighted improved links with family, friends, local services and amenities, as follows:

- 'Service' related places (local facilities and amenities) were the most commonly identified places where participants come into contact with others, with all participants identifying at least 3 places in this category. Examples given included shops, hairdressers and home visits from the chiropodist.
- Two participants identified one or two 'faith / cultural community' places, and one participant identified 5 places within the 'family & neighbourhood' category.

[37] http://www.ndti.org.uk/publications/ndti-publications/inclusion-web-resource-pack/

- Other types of places were only occasionally identified if at all; no one identified any places relating to employment (including volunteering) or education
- ‘Family & neighbourhood’ was the most dominant of all ‘people’ contacts for all participants
- ‘Faith & cultural communities’ was also a rich source of people contacts for 2 participants.

Richard and Marian’s story

Richard is 80 years old and lives with his wife Marian, who is 76. They met when working for the same building firm and lived for most of their married life in Purbeck. They moved to Drayton and Farlington 7 years ago. They have two children: a son in Manchester and a daughter in the USA with 3 children. Marian has been Richard’s main carer since he was diagnosed with Parkinson’s Disease 10 years ago. In recent years he has become immobile, unable to weight bear and finds it difficult to communicate verbally. Marian often acts as his voice; they have a warm and loving relationship, and are keen to stay living together at home. Marian has recently been diagnosed with an essential tremor, making day to day chores tricky, but is determined not to let this get her down.

The Circle discussions identified that the biggest challenge Richard and Marian face is where to go for help on a variety of issues. They are determined and practical, but didn’t know where to start to find out what was available or what they could access to help them. The inclusion web highlighted that Richard is completely reliant on Marian and his carers; his life is dominated by services which enable him to continue living at home but which leave little room for other interests. Marian’s network is broader, involving a mix of friends and the local Baptist church.

The person centred tools used to identify their goals and plan their support helped them to focus on those things that matter most to them, individually and together. This included getting help with the garden; more contact with their family; and redecorating their

home. Marian is now learning to use the internet so she can Skype their grandchildren in the States. Richard explored how to work with his carers so he can out and about more. His routine is crucial to this; if his carers don't arrive on time it completely disrupts his day and he becomes stressed. Being able to share this in a constructive way with his carers has meant they have made changes to make this happen. The garden is also under control since Marian made contact with the councils' garden waste collection service (discovered through conversation with circle members).

As Marian says, "it's one less thing to worry about, easily sorted".

Figure 7 summarises the wider population and "system" data relating to Drayton and Farlington based on data which is readily available in most public authorities and local systems. This information was pulled together in Portsmouth to highlight the impacts of different approaches adopted in the city as a result of SERI and other, related initiatives, upon wider community and service systems.

Although it is not possible to conclude that these interventions and activities necessarily contributed to the outcomes shown, this table does illustrate the range of information that is important to capture (as a starting point) in order to measure changes over time as a result of:

- having a shared vision of independent living for older people with high support needs;
- focusing on neighbourhood as well as individual networks of support in order to combat isolation and strengthen personal networks.

Figure 7: Outcome Indicators for Measuring the Impact of Older People's Networks in Portsmouth

Desired Outcome: Better knowledge and understanding about local characteristics of older people with high support needs in D&F

- Indicator: Creation / use of a ward profile capturing key characteristics of older people with high support needs
- Data / what it shows Ward profile exists and is being used

Desired Outcome: A shared vision of what independent living means for older disabled people in D&F

- Indicator (no specific indicators agreed)
- Data / what it shows Shared vision has been developed and the city wide Ageing Population Strategy refers to this

Desired Outcome: Increased wellbeing & independent living for older people with high support needs in D&F

- **Indicator** Satisfaction rates among older people with home and neighbourhood (PSA 17 / NI138)
    - **Data / what it shows** Place survey data[38]:
        a) Satisfaction with local area:
        b) 74% very or fairly satisfied with local area in 08/09, compared to 66% in 06/07 Satisfaction with home:
        c) 83% very or fairly satisfied with home (no previous data available for comparison)
- **Indicator** Reduced admissions to hospital of those 65+
    - **Data / what it shows**
        d) Admission rates (per 10,000 over 65) lower in D&F than for Portsmouth
        e) Admission rates increased in D&F over last 3 quarters of 2009, more rapidly than in Portsmouth as a whole (but in line with similar

[38] Source: http://www.portsmouth.gov.uk/media/STG_PlaceSurvey2008toplineresults.pdf

patterns in at least 5 other wards out of the 14).

f) 48% of those admissions in 2009 were emergency admissions (exactly matches Portsmouth overall)

g) Admission rates for fractured proximal femur [an indicator of falls] reduced by 20% in D&F between 2004/06 & 2007/09 (Portsmouth as a whole decreased by 9% in the same period).

- **Indicator** Reduced admissions to care homes
  - **Data / what it shows**

h) Rates vary considerably from quarter to quarter, showing strong seasonal patterns, Q4 (Jan-Mar) admissions always the highest, dropping through Qs 1-3 of the following yr

i) Comparing alike quarters, there were half the number of care home admissions in 2009 Q4 (4 admissions, 3 of whom had dementia) compared to 2008 Q4, during which there were 8 admissions) = 50% reduction

j) Q2 and Q1 admissions decreased steadily from 2008-2010

Lessons

The following points highlight the important learning from the in-depth circles of support work undertaken with individuals in Drayton and Farlington:

- Combining the use of person centred approaches in developing circles of support, with the inclusion web as an accessible, user led monitoring tool, is effective and empowering
- Working in this way needs to be paced to meet individuals' own needs and circumstances, and is well suited to and could be integrated with broader "life planning" approaches (e.g. pension planning)
- Working in this way involves huge cultural as well as potential structural changes for statutory and voluntary sector

providers who are typically contracted to “deliver a service”. These changes will take time to embed and spread across existing services, but starting small and sowing a few seeds in local neighbourhoods can help to create change that is cost effective and sustainable, e.g. by tapping into existing networks. Some additional, upfront resource is necessary for initial training and mentoring support, which can then be cascaded to other areas.

- This also involves significant challenges and change for individuals and families. Spending time talking about who you are, who is in your life and how they can help you is not a familiar or straightforward process for many people, but is helpful in identifying what’s working and not working in maintaining people’s independence and wellbeing
- The idea of a “circle of support” felt odd to most participants, who preferred informal networks that may or may not involve paid staff. They also preferred informal, often virtual, ways of coming together to explore and solve mutual problems, rather than organised “circle meetings”
- The model whereby a “circle facilitator” works with a person to establish their support and identify circle members also felt overly structured and imposed, by older people who had been used to living their life without any support. The role of an enabler or link person was, however, helpful in ensuring that the person who needs support is empowered to express their views and priorities, and to co-design the approach that will work for them. An ideal process was developed including a “person specification” for circle enablers and members (available in the resource pack, through www.ndti.org.uk).
- There is significant potential for this approach to support the take up and roll out of personal budgets, e.g. for circles to provide a low key way of enabling older people with high support needs to have and manage their budget to achieve their goals and meet their needs in ways that make sense to them. This could be further developed and tested to see if the support mechanisms established by individual older people can inform a local market of community based solutions

- The workstream group and those directly involved in this work learnt a lot about people's experiences when they are reliant on just one other person in their life (usually a spouse); in particular how fragile this arrangement is and how professionals are quick to make assumptions if something goes wrong (e.g. "if Mr X gets admitted to hospital Mrs X will not be able to cope....").

3.4 Changing the balance of power is a necessary part of increasing older people's voice, choice and control

Choice and control is about a fundamental shift in power between public services, professionals, local communities, service users and carers. There is currently a belief that independent living is about extending existing service based solutions (i.e. it's an access issue) and that professionals either know or must find out the answers to the problems /priorities identified. This is a barrier to coproduction with and to transforming the way that services are designed and delivered, and leads to workload problems for already overloaded staff. We found that the SERI sites were still at the "consultation" rung of the empowerment / participation ladder in the early stages of this work.

Moving towards coproduction and encouraging cross fertilisation between and across communities, teams, services and organisations are therefore key features of this shift in power. It requires those who retain power in public services and decision making about individual support packages to develop a different relationship with service users, local communities, colleagues and partners.

Case study – Coproducing reablement services in West Sussex

The Regaining Independence Support Service (RISS) was fully developed and implemented across West Sussex from April 1st 2010. Understanding how best to engage and learn from the experiences of older people using the service was identified as a key goal for local intermediate care and reablement services, an area typically dominated by the concerns of health and social care professionals. The aims of this work were to:

- Increase the voice of older people with high support needs to influence the development and operation of a reablement home care service in the Worthing area.
- Develop a new service that more accurately reflects the views of the older people that it serves.
- Establish regular and effective channels of communication between older people and the local authority home care service.

Key Actions

Initial plans to set up a focus group led by older people with experience of RISS to inform the development of the service proved difficult to establish. This was due to the significant and fluctuating health care needs of the individuals involved; and the relative lack of experience in engaging older people with high support needs in coproducing local services. The RISS team continued to be involved with SERI developments, learning from the cross site events and adapting the original idea of working with a co-production group to capture the views and priorities of older people using a semi-structured interview process administered by an independent researcher.

Feedback from these interviews is used by the RISS team to continually develop their approach, for example, ensuring home visits fit into older people's routines, and developing the role of support assistants to enable older people to become self managing as soon as possible.

Achievements

83% of older people with high support needs using the RISS remain at home three months after their discharge from hospital. This is an increase of 13% over last year's figures, as Figure 8 illustrates.

Figure 8: Supporting older people to stay at home after discharge

NI Measures	2008/09	2009/10
Number of people aged 65+ discharged in the given time period, and who benefited from intermediate care / rehabilitation	Figures not available	782 (six months Jul - Dec 2009)
Proportion of people at home 91 days after discharge	64.90%	83.0% (649)

Mrs W's story

Mrs W is 69 years old and was living alone at home when she had a fall in February 2010, fracturing her left shoulder, right wrist, left elbow and jaw. She had an operation on her shoulder and spent nine weeks in hospital. Before her fall, Mrs W was very active and provided a lot of support to her brother; when she first came home she was unable to do anything for herself, let alone her brother. She had particular difficulty with washing and dressing, preparing and eating meals, shopping, cleaning and getting outside.

I wanted to get back on my feet again – I wanted to be able to look after myself and to be able to go out independently again

In addition to help provided at agreed times of the day, the RISS team worked with Mrs W to gradually take more control. As she improved she was able to walk with a stick, but was not confident enough to use the bus. Someone from the team accompanied her to gradually increase her confidence and she is now able to use

the bus on her own. Her son helps with the shopping, as she is unable to carry the bags and use the bus.

This really helped my confidence; I am using the buses again on my own and am back to playing Bingo with my friends again!

Strengthened partnership arrangements between local statutory and non statutory agencies, developed through this workstream, have resulted in the RISS team and Age UK West Sussex exploring ways of extending the support available, focusing on approaches that promote social inclusion and increase choice and control for people living at home.

Lessons

The workstream group and older people involved in local developments identified the following lessons from their experiences in coproducing local reablement services:

- Invest time at the outset to scope the project or ideas for coproduction, taking into account the different perspectives, views, aspirations and collective resources of different partners and stakeholders, including older people. This took far longer than anticipated by local stakeholders, and a prevailing ‘short term’ culture proved a significant barrier.
- Ensure the work has a high profile within local organisations, securing member involvement and close alignment with other, related local developments; avoid competing for the same resources!
- Never under-estimate the importance of true partnership working and ‘partnering’, i.e. taking the time and trouble to understand different organisations' and professionals’ interests and agendas
- Acknowledge the significant gap that is likely to exist between the principles of and local practices for making engagement happen in a meaningful and sustainable way, both for those with high support needs and for staff working at the interface of health and social care

- Invest in securing dedicated local developmental capacity to make the change work in cross cutting, person centred and ‘co-productive’ ways
- Learning from other areas and examples is essential. The shared learning across the 3 sites, facilitated through interactive learning events, was extremely useful at a time of major change in local authorities and the NHS. In particular, it was important for local leads to have "difficult to have conversations" about engagement and a positive, enabling way of challenging established patterns and styles of working.

3.5 A bold vision for change needs bold leadership to make it happen

The scale and scope of change involved in applying the learning from SERI and increasing the voice, choice and control of older people is significant, wide reaching and challenging. Whilst independent living is not about services, making it happen with and for older people with high support needs will require changes within services as well as among older people, families and local communities. It requires a strong shift in policy away from a focus on “long term care” and “needs” towards citizenship, rights and equality.

Leadership across the public service system is important in achieving this change, as is leadership within teams and organisations delivering specific services. The leadership of older people with high support needs is equally important in creating the right conditions for change.

This scale of change will also require the use of mixed approaches that combine small, local developments with big ideas and strategies. It necessitates continual reinforcement of the overarching vision (of independent living) as well as evidence about the benefits and impacts for individuals, communities, services and the system as a whole.

Case Study: Getting out and about in Oxfordshire : a transport advice and empowerment scheme

'Transport' was identified as one of three key priorities from the Design Day held in Oxfordshire attended by over 100 people, half of whom were older people. Previous work, reports and strategies in the county had identified transport as a recurring, local priority, but this earlier work had not engaged the views and experiences of older people with high support needs, nor highlighted this group as a target population for whom transport and assistance to get out and about might be an issue.

Key Actions

A series of discussion groups with older people with high support needs living at home in West Oxfordshire (a large dispersed, rural area) identified their priorities for getting out and about, but also indicated that a 'whole county' approach might prove more cost effective in resolving common problems and reaching a broader base of people with diverse needs. Their priorities included:

- People need help to find out about local transport options, what help is available, and where and how to get it
- People want help to get out and about and travel more, rather than becoming reliant on services coming to them or having to move into care because they feel isolated or are considered 'vulnerable'
- Solutions need to be cost effective for individuals as well as councils
- A better understanding of how people eligible for concessionary fares/benefits experience existing transport solutions, recognising that changes to such entitlements are imminent.

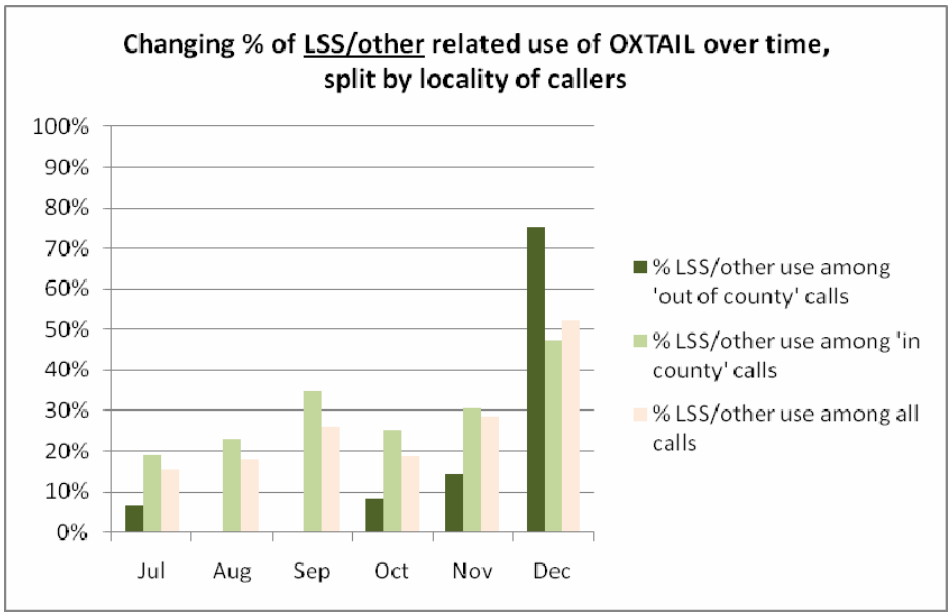
A benchmarking exercise to learn from other authorities (notably Norfolk and Rochdale) resulted in a scheme designed to help older people create their own transport solutions with assistance from a transport advisor. The focus of this role was to broker individually

tailored solutions for older people with high support needs travelling around Oxfordshire. The part-time transport adviser developed a database on transport options and secured funding for a dedicated free phone line (OXTAIL) with a linked email and web address. OXTAIL went live during July 2010, and was widely advertised via the county wide travel guide; a newsletter was sent to every household and concessionary pass-holders; and contacts were made with all known disability groups, user led organisations, impairment specific groups (e.g. stroke clubs), district councils, day centres, GP surgeries and other locally based teams.

Achievements

293 people made contact with OXTAIL in its first 6 months of operation (July-December 2010). Hospital visits are currently the most frequent reason for use (171 people, 58% of users) with the next most popular reasons being leisure, social and shopping (55 people, 19%), and these reasons are increasingly over time. The combined proportion of all health related calls (hospital, GP, clinic etc) is 71% of all calls, although these reasons are decreasing over time. This suggests people may initially contact OXTAIL for advice on health related travel, and then subsequently for wider travel reasons. The following table indicate these changes over the 6 months of operation.

Figure 9: Leisure related use of OXTAIL



There is an even spread of call from different parts of the county, although a significant number of calls (73 – 25%) are also from 'out of county'. This suggests a need for transport solutions and resources to cross administrative borders, and a pattern of people calling on behalf of older relatives and friends who live in Oxfordshire (23% of callers are aged under 65 and contact the line for someone else).

Nigel and Sue's story

Nigel is 87 and Sue his wife is 91. They live at home in a quiet area just outside the city centre, with minimum support from family and outside help. Nigel uses a wheelchair to get around, and has arthritis and asthma; Sue also has a medical condition which involves monthly blood tests and checkups. Normally a family member or close friend of the family are able to take them shopping or to any appointment they need.

Nigel was given the Oxtail number by a friend that has used the service recently and was happy with the information given. He and Sue both needed to go to their GP for their annual flu vaccine. Their son was due to take them, however due to work

commitments he was unable to take them, and Nigel did not want to cancel the appointment. He had already tried the Red Cross and St. Johns Ambulance, but both were unable to help at the time of their appointment.

Nigel feels safe when using his wheelchair outside the house, and is nervous to use public transport. This is partly due to difficulties in getting to and from their nearest bus stop, and the distance to the GP surgery at the other end. In talking about the options open to him, and understanding that public transport would not be suitable for him and his wife, Nigel and the transport advisor started to discuss other ideas, for example, a local, private Ambulance Service; or finding out if the GP or practice nurse could do a home visit as he is in the high risk category for flu.

As a result of increased confidence through talking the options through, Nigel decided that calling the GP would be the first step to seeing if they were able to give any further support. He called back later that day to confirm they had arranged for a doctor to come out with the vaccine. From this call they had also found out that if they need blood tests taken, that can also be done as a home visit.

Strategic and operational links have been established with NHS organisations, and emerging GP commissioners in particular to ensure experiences, gaps and issues relating to the majority of calls can be shared and resolved in partnership. New partnerships have also been established between this scheme, the council's Personal Budgets advisory group and the Transport Department's work on mapping routes and delivering equality and awareness training for bus drivers and confidence training for disabled people.

The council is currently undertaking an extensive review of day services following feedback from personal budget holders; from a total of 461 people with personal budgets, only 26 wanted day services to continue in their present form. As a result, the council are looking at the existing transport contract for day services (as significant resources are tied up in long term block contracts) as a possible source of future funding for Oxtail and other

developments. Ongoing funding for OXTAIL has been secured by connecting the part-time advisor post to another part time post involved in developing transport options for personal budget holders. This is helping to spread the cost, ensuring both developments are sustainable.

Lessons

The early figures demonstrate the demand and appreciation for this scheme, especially the opportunity to share concerns, talk through options and receive tailored and practical advice. The importance of building (and tapping into) local knowledge and confidence were among the most common issues highlighted from analysing the OXTAIL data and outcome stories. Other issues included: knowing what you can ask for when your options appear limited; being able to get out and about safely; and feeling confident that you can return home safely at the end of a day or evening out.

Establishing this scheme in the absence of anything similar being available locally took time and persistence from workstream group members. They attribute the success of this scheme to the following factors:

- A clear steer from older people about their priorities for change
- Actively researching and applying learning from elsewhere
- Strategic leadership to broker important links and raise the profile of the work across departments, agencies, localities and funders.
- A shared understanding that this is about more than “transport”; enabling people to get out and about is central to their ongoing independence and participation in local community and family life.
- Empowering people to solve problems and meet their own needs thereby increasing resilience, rather than reliance on a service.

3.6 Outcomes matter: measure what's important to older people with high support needs

Outcome measures and associated data monitoring processes to demonstrate things are changing and how, and to track returns on investments, need to be developed and integrated into future change programmes from the start. These outcome measures need to closely reflect what matters to older people about their lives and support; and to link these changes to wider impacts for services and local systems of support. We found that it is not the norm for staff involved in delivering services (and some of those commissioning services) to have access to 'outcome data', to share this data or to engage in discussions or exercises that facilitate a shared understanding about what "their" data is telling them.

An additional challenge is that where developments and services have been coproduced, this necessarily means that outcome indicators, and data to measure them, will relate to much broader issues and changes outside the direct control of those commissioning and delivering more traditional services. Accepting this feature of independent living and working with it requires systemic as well as cultural and attitudinal change - regarding what information is collected from where and how this is analysed, interpreted and used by whom.

There are clear connections between this Feature and leadership at all levels, including the need to clarify and widen ownership of different data sources; and develop the right conditions whereby staff working at different levels are confident and incentivised to collect, analyse and share data that links to changes in people's lives.

Case Study: Dementia Information Line in Oxfordshire

'Information' was one of the other two priorities identified at the Oxfordshire Design Day, where it was agreed that further discussion and exploration was needed with different stakeholders and partners to agree what issues or aspects of "information" needed to be addressed. A key gap in local action around the Dementia Strategy was identified, in particular the need to improve access to information and advice about dementia in order to improve knowledge, understanding and the confidence of people living with dementia and their families.

It was agreed that anything developed as a result of SERI would need to be closely connected to the introduction of dementia advisers working closely with eleven GP surgeries in the county. These dementia advisers also identified that they needed access to wider sources of information and advice as part of their role, including an information prescription system connecting those newly diagnosed with dementia to the wide range of information and advice available. A key, shared goal was the wish to raise the profile of and understanding about people living with dementia across Oxfordshire.

Key Actions

A volunteer run helpline and information system was designed to enable easier access to a range of different kinds of information and advice. The specification for providing this volunteer service went out to prospective third sector providers in January 2010, and 10 expressions of interest were received. Two organisations were shortlisted, and the Guidepost Trust was selected to run the scheme from July 2010 for two years. It took a further three months for the full service to become operational, during which time a web based information prescription (accessed via a new website called DementiaWeb), a helpline coordinator and three volunteers were recruited and in-post.

The volunteer helpline went live in October 2010, on a Monday to Friday basis with the aim of expanding this to 7 days as soon as possible. It has been publicised through local radio, libraries and information on village community websites; press releases to free and widely circulated Oxfordshire publications; posters and leaflets sent to major GP practices village halls, community shops and parish councillors; and via email to all health and social care service users and carer groups. The information prescription system has now also been adopted by other organisations operating locally, so that everyone is using the same approach and information sources are coordinated to reduce 'information overload'.

Mrs H's story

Mrs H contacted the helpline as she was extremely anxious that she may have dementia. She was reluctant to disclose any concerns to anybody, including her GP, and wanted to be able to talk her worries through with someone confidentially. The coordinator spoke with her at length, listening to why Mrs H thought she may have dementia. She emphasised the importance of ruling out other causes for confusion, memory loss etc; and explained the process of seeking a diagnosis and then being able to obtain appropriate help and support. Mrs H asked for information about different dementias to be posted to her (whilst keeping her address strictly confidential), and was invited to call back to talk through further queries and concerns. She had heard about the helpline by seeing a poster at a local bus stop.

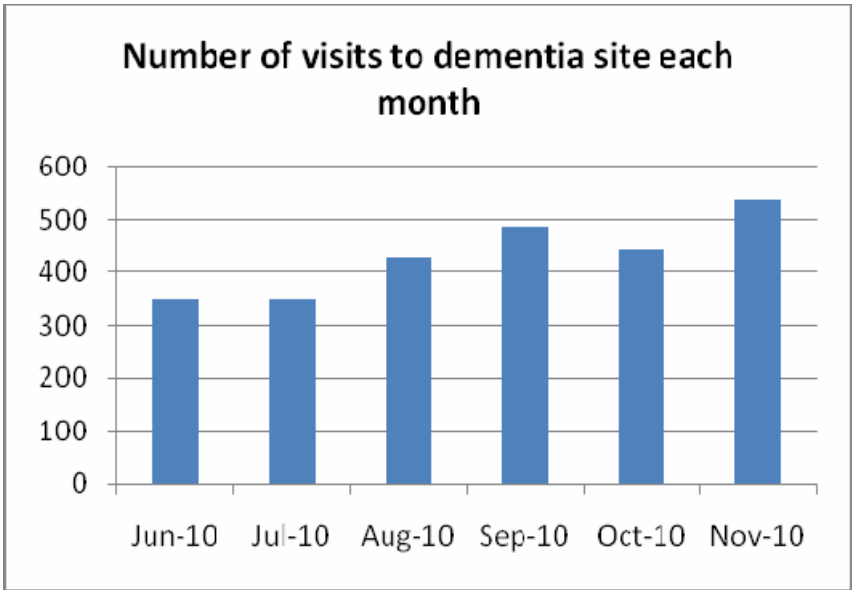
Achievements

- In the first two months, 26 calls were made to the helpline.
- The majority of direct advice and support provided has so far been to carers, often who seem to be at (or past) breaking point.
- A range of solutions has been instigated through these calls, including: new contacts with professional support; advice and

information about personalised activities; the provision of tailored information and advice

- Individuals making the calls have been able to: talk through issues with someone who is really listening to and taking an interest in them; receive information directly relevant to their queries; have an opportunity to talk through this information with someone once they've received it
- People reported contacting the service as a direct result of the 'low tech' marketing and publicity (posters, mailouts)
- DementiaWeb is seeing a steady increase of visitors, as the following graph indicates.

Figure 10: Monthly visits to DementiaWeb



Mrs G is an ex-publican and is married to a former racing driver. They live in North Oxfordshire and are "devoted to each other". They have no family, and were feeling very isolated when Mrs G contacted DIL. She had been referred to a dementia advisor and the helpline by her GP as she was struggling to cope with her husband's deteriorating condition, and was frustrated with not knowing how to manage his unusual behaviour.

Mr G was diagnosed with Dementia by his GP but refused to attend any appointments at the Memory Clinic. Mrs G felt she did not have any information and had little knowledge of dementia, and felt isolated as she had no one to talk to about it. Mrs G was given information tailored to her situation e.g. driving and dementia, diagnosis and treatments. As a result, she arranged to attend a training course on how to best support her husband and herself. The dementia advisor also liaised on her behalf with the GP and other services.

Mrs G said:

'My heart feels better now I have someone to speak to'

Lessons

People living with dementia and their families commonly feel isolated and bewildered, and it is most often this that leads them to contact the DIL. Their bewilderment is often due to the shock and worry associated with a diagnosis of dementia; a lack of understanding about what to expect in living with and supporting someone with dementia; not knowing where to go for help, or what information would help them; feeling overwhelmed with the amount of information available and how to make best use of it.

A key gap from those who have contacted the helpline is the need for assistance and independent advice in adjusting to life with dementia, and in making decisions when struggling to adjust to new life circumstances following the onset of dementia. It is clear from this analysis and the feedback from the qualitative research participants, that 'information' on its own is not enough. In all of the examples and stories collected by the scheme, it is clear that personal attention has been given to individual people contacting the service – their circumstances, likes and interests and not just the things they are struggling with. This has enabled practical and personalised suggestions to be made regarding support for the person living with dementia and their carers/family.

Sue is a nurse who is supporting a 72 year old man with dementia who lives with his wife in North Leigh. Sue was looking for a group he can attend. He has been to a ‘typical dementia group’ and did not get on well there. His wife needs a break so they were also looking for something he can do without involving his carer or needing transport. In talking about his past and interests, they identified that he used to run a post office and was very interested in photography. Sue left the call with some practical suggestions for different ways of supporting this man, including encouraging him to pursue his own interests with the help of a paid carer, and information on local dementia cafes. It was also suggested that she pass on the DIL number to him and his wife.

There is a clear need for and appreciation of this scheme, and for strong inter-relationships with local dementia networks, services and support groups. The link with dementia advisors and support workers is particularly important, as are other roles providing 1:1 support, advice and encouragement, e.g. brokers, befrienders, community organisations, user and peer led organisations. All perform similar roles and could be used to spread the word and connect up different aspects of support for people living with dementia. Important lessons have been learnt about the benefits of cross sector partnerships involving statutory, third sector and very small enterprises. These lessons also indicate a need for greater flexibility in local contracting and procurement arrangements, to ensure that small and locally based organisations are enabled to deliver locally responsive support. This includes helping to build their capacity and capability in developing systems and infrastructures, which may well need to expand and further develop as the demand for this support increases.

Ongoing data collection and monitoring to analyse the pattern of calls, provision of information/ support and follow up to establish outcomes achieved, is essential for ensuring this scheme can be sustained. Ensuring local health care organisations and GP commissioners are engaged, as well as different Council departments, will help to share the costs associated with sustaining this scheme.

A woman contacted DIL to share her concerns about her husband who has Alzheimer's and macular degeneration. Due to the adverse weather conditions they had not been able to go out as often as usual. She was finding the situation very difficult as her husband continually 'wants to go out to find his wife and children and go home'. The DIL Coordinator discussed their usual coping strategies and the issues which they were finding particularly difficult right now - the snow and the caller's health, as she had a bad cold. The caller recognised that both of their thresholds were being stretched by not being able to get out and about. They discussed what support networks she has, and it transpired that one of her neighbours is always asking if there is anything they can do. It was suggested this may be an option now, e.g could the neighbour accompany her husband on a walk in the snow so the caller could have some rest? They also discussed other calming activities. On hearing that the caller's husband loves music, the Coordinator provided her with some information about music therapy. Two further contacts were made by email to discuss ongoing coping strategies.

Case Study: A New Approach to Improving Hospital Discharge in West Sussex

Age UK West Sussex is contracted by West Sussex County Council to provide a county wide Information and Advice Service specifically for older people. When older people are in hospital, often in a position where they face having to make life changing decisions, it is difficult for them to access this service. Early discussions with partners and stakeholders involved in SERI highlighted local concerns that assessment and discharge planning processes are dominated by professional concerns and were not person centred or inclusive of older people.

It was agreed to pilot a different approach at Southlands Hospital, in Worthing. The outcomes to be achieved were:

- Ensure older people with high support needs have a say in and lead decisions about their discharge from hospital and ongoing support

- Ensure that accurate information is provided about local options
- Ensure older people receive timely and flexible services to enable them to return home after a stay in hospital
- Reduce hospital readmissions and reliance on care home placements.

Key Actions

A set of inclusion criteria[39] and a process of engaging with older people via the hospital social work team were established for the pilot. This clarity was important for developing a shared understanding of the work involved, but also resulted in the pilot approach being treated as a "new service" dependent on "referrals" being received before action could be taken. A decision was taken to try a different approach, with Age UK staff and volunteers being based on the wards during visiting times in order to distribute information and provide advice about the range of community based support and local services available to help people return and remain at home.

Achievements

During the 3 month period from August to October 2010, Age UK staff and volunteers made contact with a total of 360 patients and informed them about services and support available [this equates to a potential 1,440 people each year]. They were all left with details of how to make contact with the team. Of the 360 patients contacted, 49 [13.6%] requested and received additional support by the end of October 2010. This probably does not reflect the full potential of this approach to deliver support to more people; it will be important to keep monitoring this pattern, and explore different methods of making contact, when and by whom, pre and post discharge (and pre admission for planned admissions). Promoting the scheme to a range of professionals and service 'gatekeepers'

[39] Inclusion criteria: participants aged over 60, current inpatients in Southlands Hospital, deemed to have capacity to make decisions, and be faced with having to make significant life changing decisions.

is key in enabling this to happen (e.g. GPs, nursing, therapy and medical staff based in hospitals; hospital and community based social work teams; patient and service user and carer groups; older people's forums; other third sector providers).

The majority of information and advice requested related to financial implications of making decisions about future care and support. Follow up support included:

- 9 people received a home visit post-discharge to help with applying for benefits, in particular attendance allowance.
- 3 people received face to face advice post-discharge at one of our outreach locations
- 4 people were still in hospital at time of data returns.
- 33 people received telephone support post discharge.
- 19 people were referred onto the pension service to access additional funding for more support.
- 6 people were referred to the Good Neighbours Service, because once home they felt isolated as they did not have a network of family or friends to support them.
- Most people were also advised on and/or signposted to a variety of other organizations for assistance e.g. for obtaining a blue badge, community transport, delivery of pre-cooked meals, getting help and support in the home.

Lessons

What felt like a long time to agree an effective and responsive model for delivering this support was in hindsight a matter of months involving complex, cross agency and sector negotiations. Early attempts to link this voluntary sector led initiative with the hospital based social work team (thereby requiring a referral from the social worker in order to visit someone on the ward) reflect the dominant "professional gift model" of service delivery that exists in many hospitals, and towards older people with high support needs. The workstream group working on this development identified the following lessons from their experiences:

- Learning from similar approaches in other areas (as happened in the transport initiative) would have highlighted potential solutions at an earlier stage. Examples include the

hospital screening service developed by Help and Care in three hospitals in the south west.

- Securing the engagement of hospital and other health care staff in the Design Day and Local Steering Group discussions would have raised awareness and understanding about the aims of this work, and may have opened the door to offering hospital staff targeted development support in adopting person centred approaches and community inclusion – key features of successful hospital discharge.
- This was an area where partnership working was embryonic and the involvement of older people with high support needs in local developments was low. The readiness check for independent living (http://www.independentlivingresource.org.uk/IndependentLivingAndOlderPeopleReadinessCheck.pdf) would have been a useful, practical tool for exploring and facilitating some of these cross agency and cross sector discussions
- In spite of the above difficulties, this was an area where data collection and monitoring appeared to be more straightforward than other workstreams, and certainly easier to access in terms of readily available local and national data sets. This feature could therefore have been exploited in brokering discussions and improving partnership working between the NHS, social care and voluntary sector partners involved (e.g. involvement from the voluntary sector facilitating earlier discharge and reducing the numbers of emergency readmissions).

Case study - brokerage in Oxfordshire

To support the development, funding and use of brokers working with older people living in the participating care homes in Oxfordshire, a new set of indicators was created with a data collection and monitoring system for capturing and measuring them. This included the use of qualitative information such as stories and staff experiences to identify quantitative information which could be used to demonstrate individual and service impacts for local commissioners. Whilst the information captured is primarily “input and output” data about service and system changes (rather than changes brought about in people’s lives as a result of brokerage), these developments can be built upon to ensure that what is measured is what matters to older people with high support needs.

As highlight above, one issue which became absolutely clear during the course of SERI was the enormous potential to improve the quality of lives of many people in both community and care home settings as a result of increasing their voice, choice and control. However, this is very difficult to quantify at a population level and hence often gets ignored in major needs assessment documents, such as local Joint Strategic Needs Assessments (JSNA)[40]. The Health and Social Care Bill[41] places a legal obligation on NHS and local authority commissioners to refer to the local JSNA in exercising their commissioning functions. In addition, the Bill specifies that the new statutory Health and Wellbeing Boards[42] should develop a joint health and wellbeing strategy that spans the NHS, social care, public health and potentially other wider health determinants such as housing. Through the strategy, the council, NHS and other, local partners should agree, at a high

[40] Guidance on Joint Strategic Needs Assessment. (2007) Department of Health

[41] Health and Social Care Bill 2010-2011 (January 2011) Department of Health. http://services.parliament.uk/bills/2010-11/healthandsocialcare.html

[42] Health and Social Care Bill 2010-2011 (January 2011) Department of Health. http://services.parliament.uk/bills/2010-11/healthandsocialcare.html

level, how they will address the health and wellbeing needs of their community. The Bill places a legal obligation on NHS and local authority commissioners to have regard to this joint strategy in exercising their commissioning functions.

As many of the needs as we have identified in this report are not easily quantifiable, there is a risk that they will be ignored and therefore not inform these new strategies. However, as we have demonstrated, just because these are not easily quantifiable does not mean they are not real nor pose a significant area for health and wellbeing improvement for all localities. Authorities must redouble their efforts to measure what is important to older people with high support needs, as outlined in this report.

Chapter 4: Priorities for improving the life chances of older people with high support needs

Achieving change is the focus of this final Chapter.

Section 4.1 sets out six priorities for action that will help to ensure that independent living makes a difference to older people with high support needs. These are based on the six key Features of Change identified in Chapter 3, which are also outlined in the Summary.

Section 4.2 sets out the resources and tools that can be used to implement these actions, which have been used and/or developed as a result of working with the 3 SERI sites.

4.1 Priorities for action at a local and national level

Six priorities for action have been identified from examining the findings, lessons, and outcomes from the SERI programme. These comprise actions, mostly local and some national, which will improve the life chances of older people with high support needs.

1. Develop a shared vision for improving the life chances of older people with high support needs
2. Co-produce services and plans with older people with high support
3. Take a whole system, whole community approach to join up networks, services and resources
4. Adopt person centred approaches to drive through change and focus on older people's hopes, aspirations and priorities

5. Invest in and develop strong system, community and peer leadership to deliver the fundamental changes involved.
6. Develop meaningful outcome measures for use by 'data-confident and competent' staff and services
7. Develop a shared vision for improving the life chances of older people with high support needs

Agreement about 'what success looks like' is one of the key stepping stones for achieving change at a local level. In essence, this is about creating a broad and rich picture of life in later life if/when you need a lot of support – and the range of people who have a stake and a part to play in making that happen, including individual older people and their families. Importantly, this is not a vision about 'containment' or services, or even what "offer" local authorities and their partners can make to local older people and their families.

At a local level, this vision needs to be developed, owned and shared (i.e. co-produced with a range of stakeholders and partners including older people with a range of support needs). Talking with and about "older people with high support needs" requires local partners and stakeholders to have different conversations about older people using local services now and in the future. It encourages a citizenship focus and ethos which is crucial in shifting attitudes and behaviours, and is a central focus of local Ageing Well strategies and plans.

This takes time, commitment and energy and sticking power to stay focused on achieving a shared understanding and working through differences of opinion about competing or conflicting priorities. It does, however, pay dividends. As the work of the SERI sites has illustrated, adopting person centred approaches and promoting community and social inclusion:

- strengthens personal and natural networks of support;
- enables older people to get out and about and stay connected to family and community life;
- requires the development of personalised information and advice to/for people living with dementia;

- involves the voluntary and community sector in facilitating timely and supported discharge;
- facilitates the co-production of local services with local communities and partners, including those at the interface of specialist health and social care services.

Whilst the primary focus is on achieving change at a local level, we also believe that a high level, overarching vision is necessary at a national level, building on the independent living vision outlined in Chapter 1. The general lack of awareness and understanding about independent living and about the characteristics, experiences and aspirations of older people with high support needs is widespread and pervasive. It is influencing the tone and tenure of debate about our ageing population and the kinds of policies and strategies developed to respond to demographic change. The focus on “care”, “needs” and “who pays for long term care” illustrate this tone. Older people and local partners involved in SERI have called for a much more radical agenda and this requires a clear, national vision which is supported by policy makers, politicians, academics, innovators, funders, movers and shakers.

A simple and straightforward place to start is with a “refresh” of the existing Independent Living Vision, to make it explicit that this is an expectation for and of older people with high support needs.

Figure 11: A vision for increasing the voice, choice and control of older people with high support needs

Vision: Older people with high support needs have the same choice, control and freedom as every other citizen, and any support is based on individuals' own choices and aspirations

- Actions that increase voice, choice and control
- Greater participation in family and community life
- Equal access to housing, education, employment, leisure, transport, health and social care.

Co-produce services and plans with older people with high support needs

Increasing the voice and influence of diverse older people with high support needs has been a central feature of the SERI programme within and across the three sites. It has been challenging, powerful, energising, emotional and productive work. It has harnessed the skills, talents and contributions of older people who thought no-one would ever be interested in their views and opinions ever again. It has involved people who had felt lonely, isolated and forgotten.

One woman involved in the voice mapping exercises in one site had left her home for the first time in years to attend a workshop and get involved. Each area now has a small, but powerful force for change in the individuals and self organising groups of older people with high support needs who want to carry on influencing, informing and learning about local developments so that local services make sense to them and people they know now and older people in the future.

This was a new experience for pretty much everyone involved in the SERI sites at a local level. In our experience, this is not unique to these three areas. Good things are happening all over the country in respect of older people co-producing strategies, plans and local services. These examples rarely if ever directly engage with or involve older people with high support needs, especially those with complex needs or cognitive impairments. The SERI participants and sites have shown this is possible and is an aspiration of the people we have worked with over the last two years. The four point plan set out in Chapter 3 (see Figure 5) provides a template for local action to develop “coproduction confidence” and skills with older people living in care homes and those at risk of moving into care.

In addition, the following points summarise other local priorities and actions which can be taken to move towards a coproduction ethos and common practice:

- Adopting person centred approaches including circles of support is one way of coproducing individual support plans and delivery with older people.
- Support the development of user and peer led groups and networks of older people with high support needs – both within existing networks and as collective voices in their own right
- Recognise that a range of diverse methods are needed to encourage, amplify and promote the diverse voices of older people with high support needs. What works for other groups and at other ages and stages in life may not necessarily work the same or as well for people who are not well or who have fluctuating health in later life. We have found that "specialist tools and techniques" are not the answer to engaging people whose voices are not heard; more that ongoing tweaks and adaptations help to ensure that coproduction proceeds at and is led by the person's pace.
- The seven principles and associated practices of coproduction with older people, set out in the guide developed by NDTi and HSA[43], can be used at a local and national level to adopt and embed coproduction, and evaluate the outcomes achieved.

Finally these messages and actions, we feel, need to be shared and explored with existing networks of older people and partnership groups involving older people in policy and practice development. For example, the national partnership group on ageing and older people hosted by the Department for Work and Pensions, the network of regional fora of older people and ageing, and the vast range of local older people's forums and groups such as Speaking Up For Our Age. Two key questions for consideration in these arenas are: How can the voices and experiences of older

[43] Bowers et al (2010). *Don't just do it – coproduce and live it! A guide to coproduction with older people*. HSA Press.

people with high support needs be more easily accommodated within these networks and groups? What can these networks do to promote and engage unheard or seldom heard voices more widely?

Take a whole system, whole community approach to join up networks, services and resources

Increasing the voice, choice and control of older people with high support needs is about lives, not services. Understanding and accepting this key message has consequences for all public services and resources in terms of what gets commissioned and how. It also has consequences for local communities and the wider provision of goods and services, for example in preparing for the duties and requirements of the Equality Act 2010. In other words, this is everybody's business - and the risks, resources and rewards likewise need to be shared as well as the responsibility.

We have found low levels of readiness not only for independent living for the two target populations, but also for this degree of joint working and shared resourcing as well as risk taking. In two out of the three sites it was difficult to engage agencies and organisations beyond adult social care services, and the default position for policy and practice relating to older people is that this "belongs" in health and social care. Not only does this conflict with what older people want and what we have observed to be most effective, it is no longer viable in the current economic climate. The only way to remain creative and responsive in difficult financial times is to share resources in terms of money, people, time, skills, ideas, facilities and plans.

Oxfordshire partners have secured resources to sustain "what works" in what were new initiatives locally because they demonstrated the potential benefits of their areas of focus to different partners in transport, social care, health, leisure and the voluntary and private sectors. For example, that improving local transport options is connected to developments associated with the Big Society and GP commissioning as well as the roll out of

personal budgets and better use of community facilities; investing in person centred approaches for people living in care homes improves people's lives and local services for commissioners and independent providers.

Two specific tools are included in the resource pack which will help local partners get started on this work. The partnership readiness framework can be used by local partners and stakeholder groups to critically self assess the strengths and weakness of current partnership working and "partnering behaviours", and agree where and how to address key gaps. The readiness check for independent living and older people is based on the 6 principles of independent living with older people (see Figure 12), developed as part of the resource on independent living and older people. It can also be used by local partners and stakeholders to both increase awareness and understanding about independent living. It also sets out an agenda for change which can be used locally and nationally to take this work forward, and to explain and expand upon the overarching vision outlined in Figure 11.

Figure 12: Principles of Independent Living and Older People

1. Increase Voice: Older people need a much stronger voice to exercise choice and control in their own support and in local service developments. ‘Voice’ is the ability to express oneself, be listened to and have one's views and experiences taken into account
2. Ensure Equal Access: Commissioners, providers and local communities need to ensure older people who need support have equal access to: information, advice, advocacy & brokerage support; early intervention and preventative services; housing related support, aids and adaptations; different ways of managing long term conditions at home, in the community and in supported accommodation including extra care housing and care homes
3. Enable Choice and Control: Enabling choice and control is a key goal for those seeking to embed independent living for older people at a strategic level. This means older people having choice and control over any support they need to live their everyday lives; and staff being person centred in all they do and at all levels
4. Enable Participation: Participation in family, community and civic life is also a key goal of independent living, and is inextricably linked to people’s roles, activities, interests and relationships – i.e. what people do and who they see in their everyday lives at all ages
5. Join It Up Strategically: Professionals and agencies still work in silos. Joining it all up is a central feature of independent living. A strategic approach that looks across all areas of action, funding and needs is required to join up different kinds of support that reflect the whole of people’s lives
6. Promote a New Way of Thinking: By 2020, half the adult population in the UK will be over 50. The way we think about ageing, older people and disability needs to catch up with this demographic reality. This means moving

> away from negative attitudes that portray older people as a drain on public resources. A new way of thinking will lead to new ways of organising resources and financing models of support that make voice, choice and control a reality for everyone, and will benefit all generations.

Adopt person centred approaches to drive through change and focus on older people's hopes, aspirations and priorities

'Person centred approaches' has become a familiar phrase but the meaning and its application with and for older people with high support needs is still very under-developed. Adopting person centred approaches was a common area of focus for all SERI sites focusing on older people living in care homes, but the lessons and outcomes achieved are relevant for older people across the board. The work involved in developing natural networks of support in Portsmouth included the core person centred thinking and planning tools and skills in order to establish circles of support with older people living at home at risk of a move into care.

In spite of the rhetoric around "being person centred" we have learned that understanding and adapting practices to support older people as unique and valued human being with skills and contributions to their own as well as other people's lives was far from familiar and in some cases was seen as threatening and frightening. It blurs boundaries and involves risk; it means standing in the shoes of someone you don't know very well and working hard to get to know them and their priorities; it transforms the relationship between "the user" and (usually) the "care professional".

We found that combining the principles and practices of community inclusion with those associated with person centred approaches, helped older people and staff working with them to alter the balance of power and connect with people's lives. This was ultimately rewarding for staff and life changing for individual older people involved. Services and resources involved in commissioning, providing and paying for care can also be

fundamentally transformed by working in this way, but more work is now needed to test this out on a longer term basis in more settings and localities.

In addition to the practical tools and resources developed through SERI (e.g. the PCA and Inclusion Programme outlined in the resource pack), the following points emphasise the key lessons learnt about embedding person centred approaches in order to increase older people's choice and control:

- Embedding truly person centred approaches won't just happen by itself; there is a huge need to be proactive in reviewing local practice, experience and outcomes (to identify what's working and not working), and in stimulating change and providing development support to maintain and spread what works in enabling older people with high support needs to have a good life.
- Local change programmes designed to embed person centred approaches need to reflect the whole of older people's lives and their personal histories and life experiences. Working with older people who are currently engaged in local developments as well as enabling participation from those whose voices are currently not heard, will ensure that local decisions (e.g. about where to start and what needs to change) are driven by coproduced priorities and plans.
- As this is about improving life chances and designing support that enables people to live their life, working in person centred ways is a change that needs to engage and directly affect all public services, not just social care where it currently resides, and not just health care where the need is well documented. It applies as much to housing, transport, learning and leisure, and to broader community engagement and volunteering opportunities as it does to more specific services and interventions. Development programmes combining actions that promote community inclusion and person centred approaches help to maintain this breadth of

focus, as well as offering practical tools and resources to create the right conditions for change required.

- Finally, as the above implies, adopting person centred approaches across all public services and communities will require new partnerships as well as existing relationships to be developed and maintained. Depending on the current situation, past experience of partnership working and the pattern of connections that exist locally, this may take time to develop and/or to result in tangible change that people can observe and measure. Identifying, agreeing and communicating the first steps and early signs of change together will help to keep people on track as they develop new ways of working and wider opportunities for support.

Invest in and develop strong system, community and peer leadership to deliver the fundamental changes involved.

Strong, confident and empowering leadership is central to moving things forward – both at a practical level in day to day support, and at a strategic level to ensure the right people are involved and resources mobilised and used to best effect.

Personal stories and case studies illustrating what's important and what can be achieved as a result of increasing voice, choice and control can help to promote and stimulate the leadership styles and capabilities require.

Specific leadership tasks associated with this programme of change include: the development and delivery of a local, shared vision of independent living with and for older people with high support needs; shifting attitudes and prevailing cultures where older people are seen as passive recipients or 'vulnerable' and in need of care; and changing practice which perpetuates these cultures and resists change towards enabling and empowering services and support. Leadership across the public service system is important, as is leadership within teams and organisations delivering specific services.

Creating and promoting opportunities to develop and use the leadership skills and capacities of far greater numbers of older people with a diversity of experience, background and support needs is also crucial. The SERI sites found that the greatest impetus for change most often came about as a result of hearing the direct voices of and engaging older people in local conversations about services .There is a need to grow the numbers, skills and confidence of many more older people with high support needs in all areas in order to create the critical mass required so that independent living becomes the norm, not the exception.

Develop meaningful outcome measures for use by ‘data-confident and competent’ staff and services

There is a plethora of data and information that is collected within and about local services and the characteristics and needs of local populations. We found little evidence of this intelligence being used, or of it being translated into relevant and interesting information that commissioners and practitioners and local leaders could access or interpret to inform their decisions. It was not being made available to or engaging local communities or the target populations.

It proved difficult but not impossible to develop clear, shared outcome measures relating to independent living and how this impacts on older people with high support needs. This is both at a local and a national level. Services and systems are encouraged to collect and most familiar with input and output data: numbers that reflect how much / many of something is provided / accessed / undertaken by how many people and at what cost. Some of this information is also not available or difficult to access. More importantly, talking about and measuring outcomes and impact – the difference these interventions and/or activities make to someone’s life and to wider services – is a new and unfamiliar concept in this field.

The following steps and actions will help to address this gap, and to build on the lessons and achievements of the SERI sites:

- There is scope to develop one, contained set of outcome indicators and measures that can be used at both a local (ongoing) and national (annual) basis, focusing on improving the life chances of older people with high support needs as a result of increased voice, choice and control. Having fewer 'indicators of change' (outcomes) that reflect positive differences in the lives of older people with high support needs, and measuring them well would not only be easier and less expensive at a local level but would enable changes over time to be observed (e.g. to establish returns on investments made). Through SERI we have developed an exhaustive bank of potential indicators that people could refer to, and which could be used as a starting point for developing a simple set of outcome measures on independent living and older people.
- Within the above, there is a need for a much greater focus on outcome data including clarity about: who or what the outcome/change is for (often a mixture of short and medium term changes); the consequent outcomes/changes for services and the system (also often shorter and medium term changes); and the changes it is hoped that the system outcomes will bring about for individuals and whole populations (usually longer term changes, or impacts). A simple way of keeping a focus on outcomes rather than outputs is to keep asking, 'so what difference will this make for people with high support needs'?
- In order to secure buy in and achieve added value from these outcome measures, it would be helpful to discuss this proposal with national advisors and those with expertise in outcome measurement. This would have implications for national data collection and analysis as well as local data collection and analysis (ie less focus on volume measures and trend analysis based on volume measures; greater focus on outcomes for individuals and the system as a whole).
- In order to make this information accessible, practical and engaging at a local level, learning resources and exercises

designed to engage a range of partners and stakeholders could be used to develop a shared understanding and agreement about what to measure and collect across the local system. Case studies of “good data” and “poor data” could be used facilitate discussions and broker these agreements; and outcome frameworks that enable partners to collect, analyse and track changes over time would help to keep these activities simple, effective and efficient. The 5 layers of evidence framework could be used to help achieve a balance of different sources of data/information to build a picture of what’s working for whom, why and how[44].

- Finally, there is a need to develop much better information and intelligence about local populations of older people with high support needs, and to engage the full range of existing and emerging commissioners and providers in its use. For example, promoting the use of ‘POPPI’ - Projecting Older People Population Information - designed to give councils with social service responsibilities easy access to forecasts of the numbers and characteristics of older people in their locality[45]. Recent work on establishing the key national trends and characteristics of older people with high support needs is relevant here, but would benefit from further disaggregation into what this means at a local and regional level[46].

[44] The 5 layers of evidence framework was designed by Dave Burnham, Head of Information at Lancashire County Council to assess the overall impact of self directed support at a local level. This approach is highlighted as good practice by the Department of Health as it takes a holistic approach to measurement, which fits with the independent living agenda.

[45] http://www.dhcarenetworks.org.uk/csed/dfAndCapacityPlanning/poppi/

[46] Falkingham, J., Evandrou, M., McGowan, T., Bell, D. And Bowes, A. Demographic issues, projections and trends: older people with high support needs in the UK. JRF Programme Paper: A Better Life. October 2010

4.2 Resources and tools for achieving change

The learning from SERI identified that for independent living to be a reality for older people with high support needs, the following key steps are essential:

- Local partners and stakeholders need to agree that there is a need for change, which implies that the current situation (e.g. as mapped out in this report) needs to be fully grasped and understood;
- Once this has been, then the same partners and stakeholders need to work together to agree what needs to change and how;
- Agreeing these priorities and working through a structured action planning process will ensure that the first practical steps for getting started are more likely to happen quickly and effectively than either doing this separately or in too loose a manner;
- This process needs a specific focus on identifying and agreeing both the desired outcomes from these actions, and measures that will show whether these outcomes have been achieved, how and why.

A resource pack has been developed to pull together the various tools and resources developed during and/or as a result of SERI, which can be accessed at www.ndti.org.uk.

This resource is designed for:

- people responsible for commissioning public services (not just health and social care), including those responsible for planning and shaping local services and opportunities for support;
- people directly involved in “older people’s” services and ageing strategies at a local level;

- older people, including those with high support needs, who are involved in local service developments and decision making;
- people with an interest in older people's experiences and preparing for an ageing society;
- people with an interest in increasing the voice, choice and control over any support people of any age need to go about their everyday lives.

The wider public (older people, family members/carers, society generally, and the media) constitute a secondary audience, for whom some aspects of the resource pack will be of interest and practical use.

The resource pack is a combination of materials, guides, tools and resources that help these audiences to:

- Increase their knowledge, awareness and understanding about independent living and about older people with high support needs
- Change/influence attitudes and beliefs about older people with high support needs and independent living
- Show how to increase the voice, choice and control of older people with high support needs at all levels (individually and collectively)

The following summary provides an outline of the main sections and contents of the pack.

Section 1: Creating a shared understanding of independent living, older people with high support needs

- A clear vision focusing on improving the lives and life chances of older people with high support needs
- Tools and exercises that help partners/groups understand and define "independent living" and "older people with high support needs"

- Tools and approaches /exercises that help to create a shared vision about: the need for change; what needs to change; how to achieve that change.

Section 2: Achieving change at a local level, including:

- Identifying and agreeing shared priorities
- Agreeing outcomes and how to measure them
    - Linking outcome indicators – logic models
    - Tools to aid reflection and learning from data
    - Process for exploring messages and what data is telling us – focus more on the building the process and creating the conditions for people to think in this way
    - Case studies of good data systems linked to outcomes
    - Various monitoring frameworks used in the sites
- Review frameworks that ask: how are things going, what are we learning, what are we pleased and concerned about, what will we do next?
- The use of reflective diaries
- Demonstrating what's possible through case studies/stories

Section 3: Adopting person centred approaches and achieve community inclusion for older people living in care homes,

Including:

- Outline of the Training and development programme on Person Centred Approaches and Community Inclusion used within SERI
- Person centred thinking and planning tools used in the sites
- Costs associated with implementing this and benefits achieved
- Templates people can use to help get started
- Where to go for further info/advice

Section 4: Increasing the voice, choice and control with and for older people with high support needs living at home and in local communities:

- Practical and inclusive methods for identifying, reaching and engaging older people with high support needs (both target populations)
- Identifying/mapping and securing commitment and access to all resources available in local neighbourhoods/localities, in order to increase the voice, choice and control of older people with high support needs
- Building, developing and maintaining effective partnerships with public services, local communities, voluntary and private/commercial sector partners
- Models and approaches that help to achieve the above, and deliver better outcomes for older people with high support needs, families and communities, local services and the state
- Lessons and stories – from the 3 sites and from elsewhere

Section 5: Increasing the individual and collective voice (and influence) of older people with high support needs,

including:

- Raising awareness and understanding about independent living (voice, choice and control)
- Mapping and gathering information about the current level of influence and mechanisms for older people to increase their voice: a) in their own support; b) in local communities and service developments; c) in wider strategic planning and decision making
- Working with individuals and groups to identify what works, what doesn't work and agree priorities and solutions
- Building confidence, developing skills and supporting older people through a coaching and mentoring programme
- Widening and sustaining older people's individual and collective voices

Section 6: Tools for carrying out research with older people with high support needs, including:

- Keys to a good life indicators
- Topic guides relating to the above
- Sampling matrix and monitoring arrangements
- Participant information and information packs
- Recruitment strategy and arrangements
- Graphic and easy read tools to aid discussions
- Analytical tools
- The use of reflective diaries.

Each of these sections contains information, tools, tips and downloadable materials, organised as follows:-

- Background (how things should be – policy intent and/or older people's priorities)
- The current situation (what we have found out through SERI)
- What needs to change? (for whom, at what level)
- How to achieve this (the tools themselves)

References

Blood, I. (2010) Older people with high support needs: how can we empower them to enjoy a better life? Joseph Rowntree Foundation's Better Life Programme.

Bowers, H. et al (2009). Older People's Vision for Long Term Care. Joseph Rowntree Foundation

Bowers, H. et al (2009) Personalisation: don't just do it – coproduce it and live it! A guide to coproduction with older people. HSA Press

Chapman, Sherry Ann and Peace, Sheila (2008). Rurality and ageing well: 'a long time here'. In: Keating, Norah ed. Rural Ageing: A good place to grow old? Bristol, UK: The Policy Press, pp. 21–32.

Department for Communities and Local Government (2006) Sure Start to Later Life: ending inequalities for older people. A final Social Exclusion Unit Report (2006)

Department of Health (2009) Personal budgets and older people: making it happen

Department of Health (2007) Guidance on Joint Strategic Needs Assessment

Department of Health (2011) Health and Social Care Bill 2010-2011

Dunning, J. (January 2010) Early intervention schemes lead to better health: Bradford and Tameside show the way for NHS-council partnerships Community Care

Garwood, S (2010). A better life for older people with high support needs in housing with care

Greig R. and Poxton, R. (2001) From joint commissioning to partnership working – will the new policy framework make a difference? Managing Community Care. 9(4): 32-38

Falkingham, J., Evandrou, M., McGowan, T., Bell, D. And Bowes, A (2010). Demographic issues, projections and trends: older people with high support needs in the UK. JRF Programme Paper: A Better Life.

Heywood, F. (2001). Money well spent: the effectiveness and value of housing adaptations. The Policy Press

Hurstfield, J. et al (2007). The costs and benefits of independent living. Office for Disability Issues

Mayhew, L. (2005). Active Ageing in the UK – Issues, barriers, policy directions Innovation: Journal of Social Sciences Research. Volume 18, Issue 4 (pp455-477);

Mental Health Foundation (2009) All things being equal: age equality in mental health care for older people in England.

Office for Disability Issues (2008) Independent Living Strategy: a cross government strategy about independent living for disabled people.

Percival, J. (2010). Attitudes to frailty, disability and end-of-life in housing with care

Risk Solutions (2008). Independent Living Action and Learning Sites Scoping Study: a report for the Office of Disability Issues.

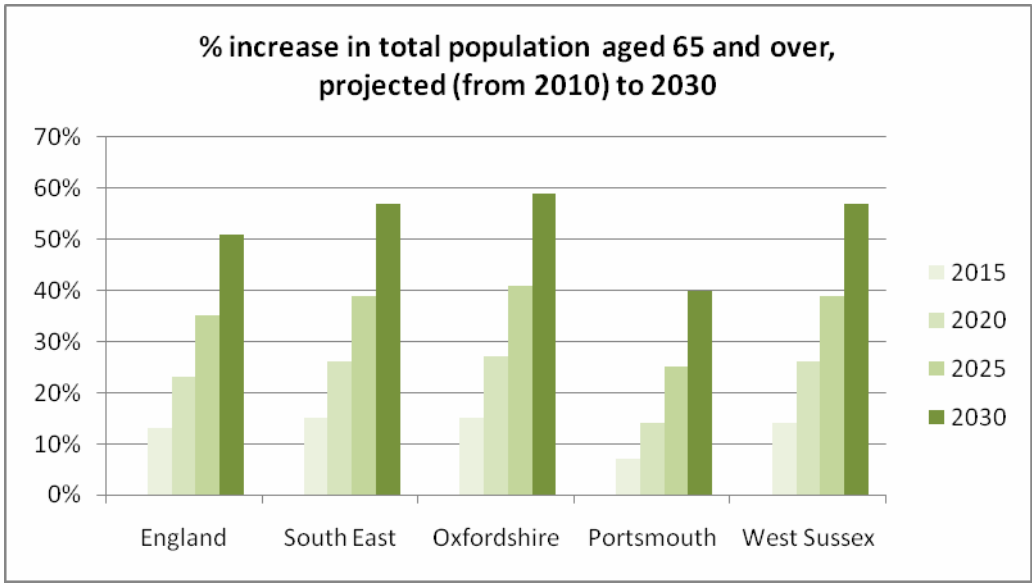
Scottish Executive (2004) Overcoming the obstacles to the improvement of dementia care: report of the Scottish Executive and Alzheimer Scotland Short Life Working Group

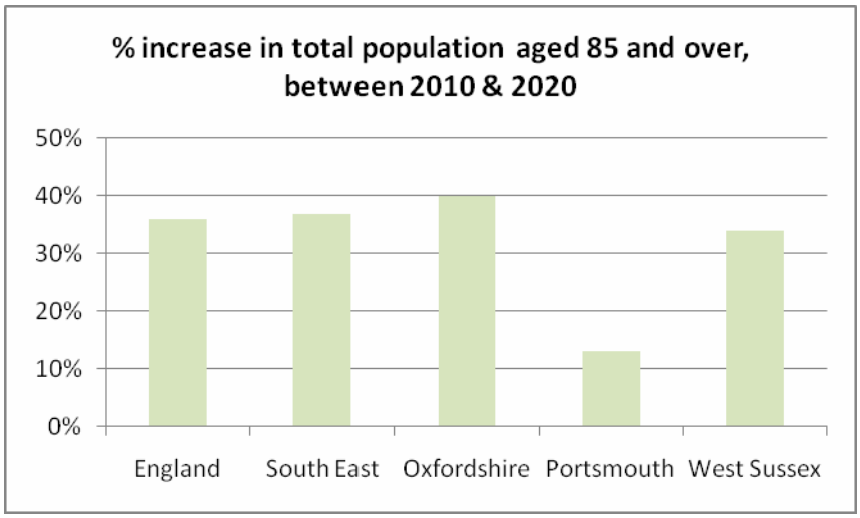
Wanless, D. et al (2006) Securing Good Care for Older People: taking a long term view. The King's Fund.

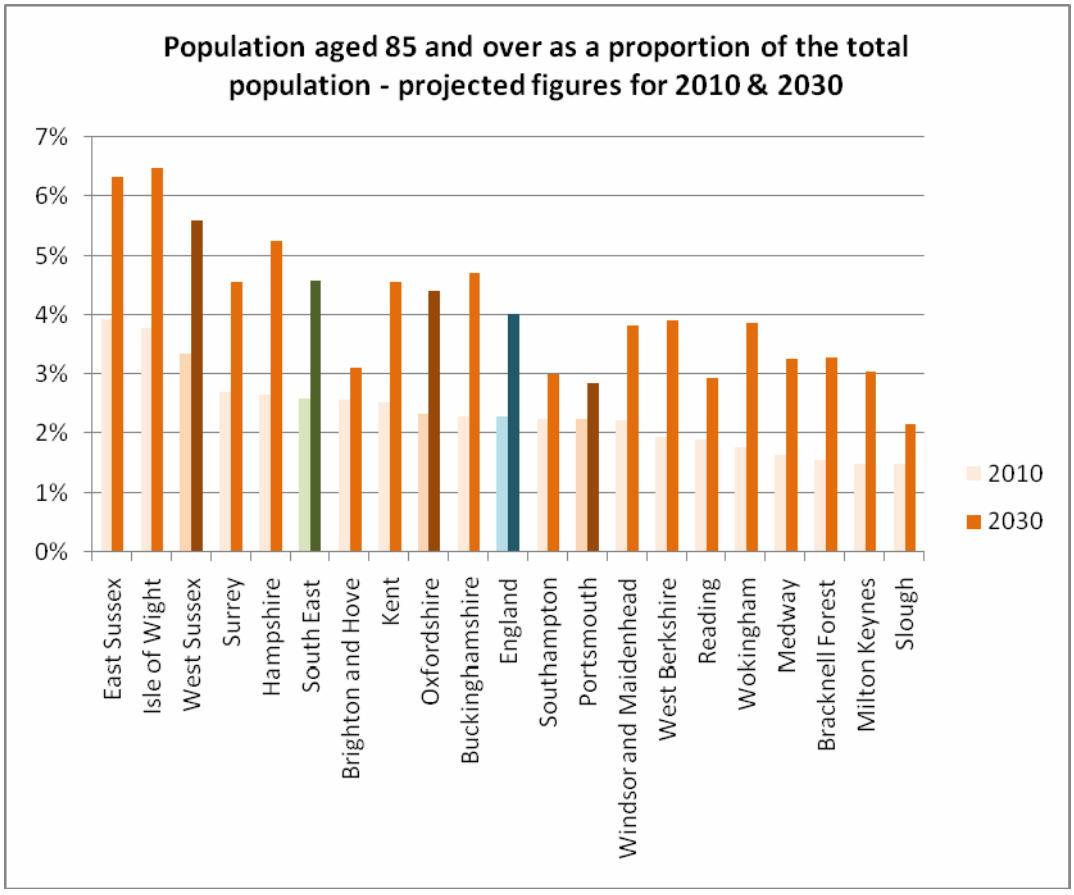
Appendix 1: Key demographic characteristics of the South East and SERI Sites

The South East region has the largest absolute numbers of people aged over 65 and 85 in the country. In addition, it has and will continue to have (taking into account long term population projections, taken from www.poppi.org.uk version 5.0). Key features of these trends that have particular relevance for the SERI programme include:

- Over one third of the population in the South East (almost 3 million people) are aged 50 and over. This is greater than the number of under 25 year olds (just over 2.5 million) (ONS, 2008 Mid-year estimates)
- This figure includes around 1,400,000 people aged 65 and over (16.7% of the total population) and over 200,000 people aged 85 and over (2.5% of the total) (ONS, 2008 Mid-year estimates)
- By 2030, it is projected that 22.8% of the population in the South East (almost 2,250,000 persons) will be aged 65 and over and 4.3% (around 425,000 persons) will be aged 85 and over (ONS, 2006-Based Subnational Projections)
- Of the SERI sites, West Sussex has, and will continue to have, the highest proportion of over 65's and 85's and Portsmouth has markedly the lowest. However, as the following graphs indicate, it is Oxfordshire out of the 3 SERI sites, which will experience the highest relative increases (ie rate of increase) both in over 65s and even more so in over 85s.


% increase in total population aged 65 and over, projected (from 2010) to 2030
70%
60%
50%
40%
30%
20%
10%
0%
England
South East
Oxfordshire
Portsmouth
West Sussex
2015
2020
2025
2030


% increase in total population aged 85 and over, between 2010 & 2020
50%
40%
30%
20%
10%
0%
England
South East
Oxfordshire
Portsmouth
West Sussex



The following key features are important region-wide characteristics pertinent to the South East Regional Initiative.

General demography

- Male life expectancy at age 65 in the South East is the highest in England at 18.4 years, and female life expectancy the second highest at 21.0 years (ONS Regional Trends 2009; GOSE PSA17 data, 2009)
- The proportion of males among all people aged 65+ currently stands at between 43.3% (West Sussex) and 44.4% (Oxdfordshire), with the national and regional averages being around just over and under 44% respectively
- In all areas over the next 20 yrs there is projected to be an increase in the proportion of this age group who are male (and a corresponding decrease who are female). The extent of this increase varies from 0.7% in Oxfordshire to 2.9% in

Portsmouth (compared with increases of 1.9% nationally and 1.7% regionally)

- In all sites, the projected increase in males is greatest between 2010 and 2015, and the rate of increase tends to level off (if not slightly decrease) between 2025 and 2030.
- The two slight deviances to this pattern are Oxfordshire (where the percentage of males actually decreases back to pre-2015 proportions between 2025 & 2030) and West Sussex (which is still showing a significant increase between 2025 & 2030) - suggesting that the national pattern might be playing out over slightly shorter / longer time periods in these two counties respectively
- Relative percentages of the 65-74 age group are set to increase up to 2015 and then drop back down to lower than current percentages in 2025, before picking up again slightly towards 2030. This decrease is especially marked in Oxfordshire (in line with national and regional averages) but less dramatic in West Sussex and Portsmouth.
- 13% of people over state pension age (208,000 persons) were still in work in the South East in 2007/8, and the majority of future population growth will be accounted for by people aged over 65. In 2008, the ratio of 'economically inactive' people to those of working age was 6:10; by 2020 it is forecast to rise to 7:10. Encouraging more people to stay in work beyond the age of 65 would help to counteract the effects of this rising 'dependency ratio' (ONS. 2006-Based Subnational Projections)
- In all areas there is a significantly higher percentage of people from non white ethnic groups among 65-74 yr olds, than among those aged 85+; assuming life expectancy is the same for the different ethnic groups, this means it's likely that over the next 20 years the percentage of people aged 85+ from non-white ethnic groups will significantly increase.
- The South East as a whole is much less ethnically diverse in these age groups than England as a whole
- All three SERI sites appear to be more ethnically diverse in these age groups than the South East as a whole, but still much less diverse than England overall

- Out of the SERI sites, Portsmouth has the highest percentage of non-white ethnic groups among 65-74 yr olds, but the lowest percentage of non-white groups among people aged 85+
- Hence, of the 3 SERI sites, the trend identified in 1a. above might be particularly accentuated in Portsmouth
- Oxfordshire and West Sussex follow similar patterns of relative proportions of different ethnic groups as England as a whole
- However once again Portsmouth is slightly different, with a higher relative percentage of 'Chinese / other' and 'Asian' compared to 'Black/Black British'
- This is particularly obvious in the 65-74 age group, though the 85+ age group in Portsmouth also shows a relatively large percentage of 'Chinese / other' communities.

Living arrangements

- An estimated 46% of women and 26% of men aged 65 and over in the South East live alone (ONS General Household Survey 2007 data)
- The percentage of people living alone increases with age and is a significant risk factor for moving into a care home. 70% of women over 85 in the South East live alone.
- Older men are more likely than older women to be socially isolated:
    - an estimated 21% of men and 13% of women aged 65 and over in the South East report a ‘severe lack’ of social support, while 40% of men and 33% of women have low levels of contact with friends, and 15% of men and 11% of women have ‘low’ levels of trust in people in general (Health Survey for England, 2005)

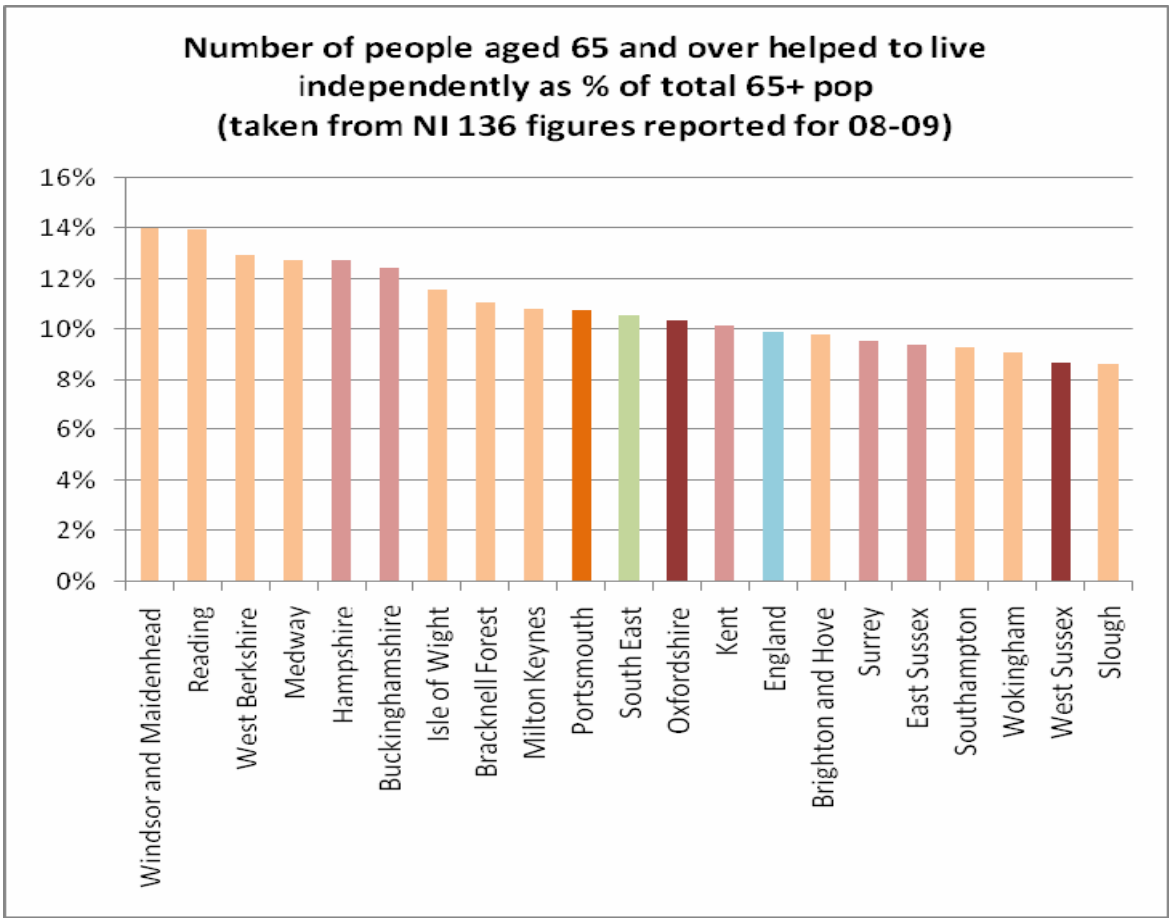
General health and wellbeing

- 26% of people aged 60-64 years report having a limiting long-term illness; rising to 40% of those aged 65-84, and 70% of those aged over 85 years (GOSE/SEPHO report: Older people in the South East Region, information from the 2001 census, 2004).
- An estimated 40% of men and 29% of women aged 65 and over in the South East have some form of cardiovascular disease and almost 10% of men and over 5% of women live with a longstanding condition caused by a heart attack or stroke. 31% of men and 44% of women over 65 years have arthritis and 10% of both sexes have some form of cancer (GHS 2007 data; Health Survey for England, 2005)
- An estimated 27% of people aged 65 and over in the South East drink on five or more days a week, the highest percentage in England; an estimated 4% of older people in the region are binge drinkers (General Household Survey, 2003-4)
- It is estimated that only 35% of people aged 65 and over in the South East consume the recommended five or more portions of fruit and vegetables a day – and this is the second highest percentage in England (Health Survey for England, 2005)
- According to GP records, over 36,700 people in the South East have been diagnosed with dementia (IC, 2006/7), although this is likely to be a considerable underestimate of the true prevalence: based on estimates contained in the National Dementia Strategy, there are 92,700 people in the region living with dementia.
- The South East has the second highest hospital admission rate for depression among women aged 65 and over.

Care and support

- Men and women aged 65 and over in the South East are in contact with their GP an average of 7.5 times a year, while an estimated 52% of men and 46% of women have attended hospital as an outpatient in the last year (Health Survey for England, 2005).
- Many people over 65 are informal or family carers, with up to 17% of people over 50 years carrying out more than 50 hours of care each week in some areas.
- Just over 1 in 5 women and 1 in 10 men aged over 85 live in medical or care "establishments".
- There are approximately 214,000 people aged 65 and over in the South East in receipt of local authority social care services of whom:
    - 176,500 (82.5%) have a physical disability or a sensory impairment
    - 184,200 (86.1%) are receiving community-based services
    - 23,000 (10.7%) are receiving residential care
    - 15,900 (7.4%) are receiving nursing care
    - 10,500 (5%) are receiving a meals service
    - 34% of men and 43% of women aged 65 and over in the South East report having a mobility problem (Health Survey for England, 2005)

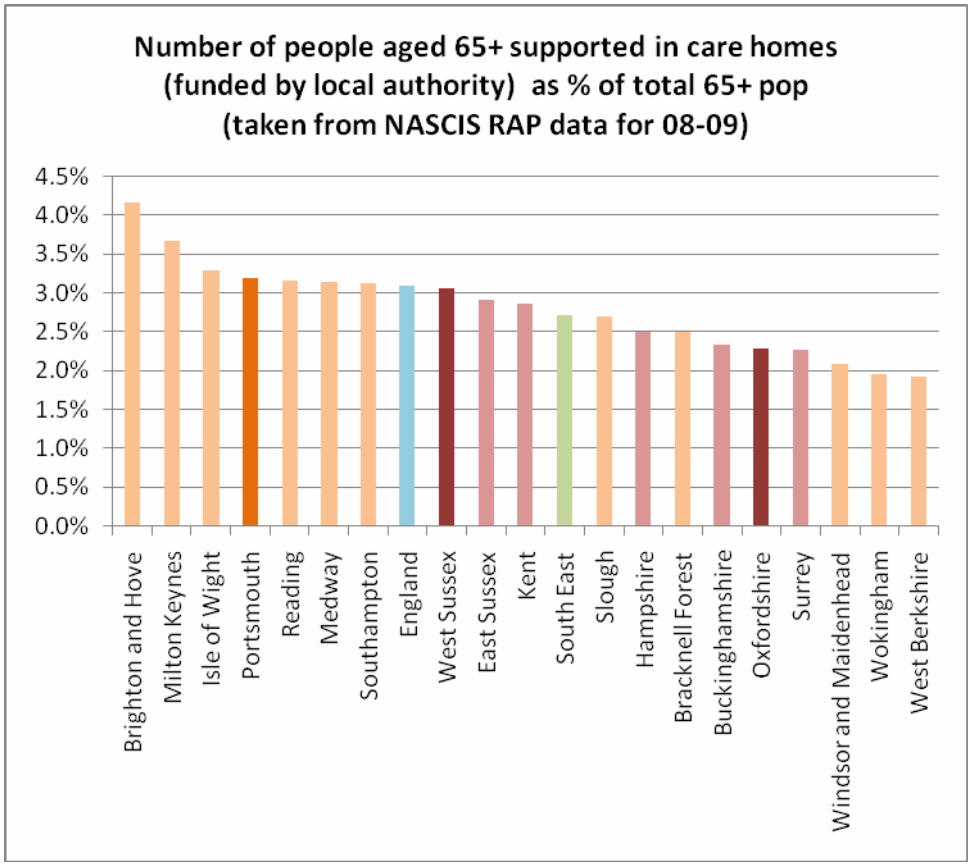
People Helped to Live Independently



- The South East as a whole (green - 10.6%) has slightly higher percentage of the 65+ population who are helped to live independently than England as a whole (blue - 9.9%).
- Oxfordshire and Portsmouth very closely represent the SE as a whole, but West Sussex (at 8.7%) has the second lowest percentage of people aged 65+ who are helped to live independently out of all other South East authorities

Proportion of older people supported to live in care homes

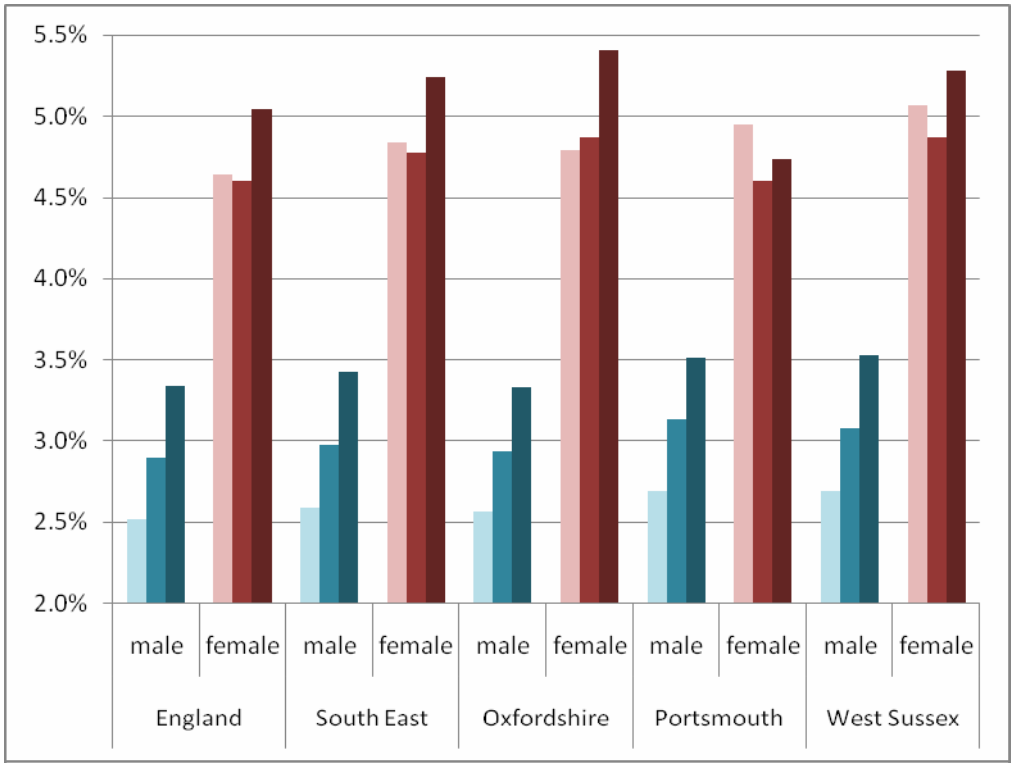
- The South East as a whole has a slightly lower percentage of people supported by local authorities in care homes than England as a whole
- SERI sites reflect a good spread of South East authorities in this respect, with Portsmouth showing the highest (3.2%), closely followed by West Sussex (3.05%). Of the SERI sites, Oxfordshire shows the lowest percentage of people receiving LA support in care homes (2.3%)
- All the SE County Councils (shades of plum) show a lower percentage of people aged 65+ supported in care homes than the figure for England overall, whilst the majority of SE Unitary Authorities (7/12) have a higher proportion than England generally.
- Possible factors for this trend:
    - Care homes being more likely to be located in or close to major centres of population
    - A higher proportion of people living in urban centres being eligible for state funded /social care support from local authorities than in rural areas (e.g. more owner occupiers in rural areas, larger populations of older people on low incomes living in inner city areas)


Number of people aged 65+ supported in care homes
(funded by local authority) as % of total 65+ pop
(taken from NASCIS RAP data for 08-09)
4.5%
4.0%
3.5%
3.0%
2.5%
2.0%
1.5%
1.0%
0.5%
0.0%
Brighton and Hove
Milton Keynes
Isle of Wight
Portsmouth
Reading
Medway
Southampton
England
West Sussex
East Sussex
Kent
South East
Slough
Hampshire
Bracknell Forest
Buckinghamshire
Oxfordshire
Surrey
Windsor and Maidenhead
Wokingham
West Berkshire

Proportion of people living with dementia

Total aged 65 and over predicted to have dementia

Total aged 65 and over predicted to have dementia						
Area	Gender	2010	2015	2020	2025	2030
England	male	216,169	257,216	306,571	365,029	431,735
	female	398,547	435,015	486,808	561,635	652,634
	overall	614,717	692,231	793,379	926,664	1,084,369
South East	male	37,941	45,728	54,946	65,920	78,577
	female	70,867	78,141	88,182	102,613	120,388
	overall	108,807	123,869	143,128	168,533	198,965
Oxfordshire	male	2,598	3,137	3,766	4,504	5,359
	female	4,846	5,442	6,243	7,320	8,694
	overall	7,444	8,579	10,010	11,824	14,053
Portsmouth	male	749	865	992	1,142	1,361
	female	1,375	1,393	1,458	1,627	1,836
	overall	2,124	2,258	2,450	2,769	3,197
West Sussex	male	4,481	5,330	6,427	7,685	9,199
	female	8,432	9,136	10,183	11,755	13,784
	overall	12,913	14,466	16,611	19,439	22,982


5.5%
5.0%
4.5%
4.0%
3.5%
3.0%
2.5%
2.0%
male
female
male
female
male
female
male
female
male
female
England
South East
Oxfordshire
Portsmouth
West Sussex

Appendix 2: Timelines of Key Phases, Activities and Deliverables for SERI

Phase 1 - Project Set Up: November 2008-March 2009

- Developing relationships and securing commitment from all the major partners and stakeholders in each site
- Holding a “Design Day” with each Site, bringing local stakeholders together to identify priorities for change (areas of focus) for the target populations
- A one day launch event involving all three sites in March 2009
- Aims and outcomes agreed with each site as the basis of a Memorandum of Understanding (MOU) and local action plan
- Local steering groups established who, together with work stream groups, drove forward change within the sites
- Sampling matrix agreed for recruiting participants for the qualitative research
- Submission for ethical approval made regarding the qualitative research (approved June 2009) including detailed research protocols, fieldwork schedules and an analytical framework
- Dedicated web resource established for sharing information amongst SERI constituents (the 3 sites, the change management team, the qualitative research team, the data analysts, project board members)
- First quarterly progress report produced for the national Project Board

Phase 2 - First cycle of change and learning: April - September 2009

- First stage of a 'Person Centred Approaches' (PCA) development programme for the care home work streams held in all 3 Sites
- Two of the work streams focusing on older people with high support needs living at home initiated (making transport arrangements more accessible; developing information, advice and advocacy support for people living with dementia)
- Mapping exercise undertaken to establish current experiences of older people with high support needs in exercising voice at an individual and collective level
- Progress review undertaken with the 3 sites using an Appreciate Inquiry framework, called "Four Plus One"[47]
- First round of qualitative research fieldwork undertaken focusing on the care home work stream in each Site
- ODI analysts visit each site to learn more about their workstreams and agree quantitative data that would be useful for sites to collect
- National Analytical Advisory Group established to advise on methodological issues arising from both demonstration projects.
- First action learning event held to share progress, issues and solutions to barriers experienced across all elements/sites
- Second quarterly progress report produced for the Project Board.

[47] The 4+1 framework asks and records: What have we tried? What have we learned? What are we pleased about? What are we concerned about? Given the above, what shall we do next?

Phase 3 - Second cycle of change and learning: October 2009-March 2010

- PCA development programme continues with specific sessions on community mapping/social inclusion, focusing on what's changing for individuals and participating homes
- A shared vision and outcomes for adopting a neighbourhood approach to independent living agreed, and actions for establishing circles of support for older people with high support needs living alone in one area in Portsmouth identified
- A Regaining Independence Support Service (RISS) developed based on views, experiences and preferences of older people, in West Sussex
- A four point action plan for increasing the individual and collective voice of older people with high support needs agreed with all sites
- Internal, baseline report for the qualitative research programme completed. Delays in establishing the community based workstreams delayed recruitment of this sample of research participants; first round of data collection for these 4 work streams completed and analysed by the end of May 2010. Second round of research visits begin for care home workstreams.
- Draft "Evidence grid" drawn up following visits to help sites identify and agree the data they can collect.
- Second Action Learning Event held, focusing on shifting power; increasing the direct voice and leadership of older people with high support needs; sustainability; and keeping hold of the independent living vision in difficult financial times.
- An interim report produced for the Project Board, and summary paper of wider lessons disseminated via websites and briefings.

Phase 4 - Third cycle of change and learning: April 2010 –October 2010

- Third and final action learning event held focusing on sharing outcomes achieved, lessons learned and priorities for sustaining what works.
- Third round of the qualitative research fieldwork undertaken for the care home workstreams, and the second round for community based workstreams
- Final round of change management support provided to sites, including a focused mentoring and coaching programme for older people with high support needs to ensure their ongoing involvement in local developments and decision making.
- Phase 5- Analysis of findings and reporting/disseminating outcomes: November 2010-March 2011
- A Findings Report from the qualitative research produced in December 2010, for publication and dissemination to agreed target audiences
- Final, integrated report covering all elements of SERI produced in January 2011, for publication and dissemination to agreed target audiences
- Key messages, lessons and findings presented to the ODI project board at the final Board meeting in February 2011
- Resources and materials produced relating to key messages and stories of “what works” and how this achieved and sustained, and integrated into the web based resource on independent living and older people (RILOP).

Appendix 3: Aims, Methods and Findings from the Qualitative Research

The overarching aim of the qualitative research was to find out and record the impact of increased voice, choice and control on individuals' experiences and opportunities for independent living. This included finding out what changed for older people with high support needs living in care homes and those at risk of moving into a care home, as a result of the work carried out within and across the three sites.
The research focused on two main questions:

1. What are the experiences and feelings of voice, choice and control like now amongst these two populations; and what are the key influences on these experiences and feelings?
2. What is changing or has changed as a result of the mechanisms, interventions, options and opportunities for increasing the voice, choice and control of older people with high support needs? What has helped or hindered?

It built on evidence from research funded by the Joseph Rowntree Foundation[48] which presented older people's vision of what a 'good life' looks and feels like to them. The "Keys to a good life for older people with high support needs" - as this vision is known - were used in the current research to inform the design of the methodology and to analyse the findings.

In total, 63 older people with high support needs took part in the research. Over the research period a total of 99 research interactions were carried out, including interviews and focus groups. These interactions took place either once, twice or three times with each person.

This sample of 63 people had the following characteristics:

[48] Older people's vision for long term care Bowers et al, November 2009, Joseph Rowntree Foundation www.jrf.org.uk

- There was a fairly even distribution of participants across the two target populations, although more repeat interviews took place with people living in care homes; the neighbourhood workstreams took longer to get going, leading to delays in identifying and recruiting appropriate participants;
- Of the 63 participants, 40 (63%) were female, and 23 (37%) were male, mirroring population figures for the South East of England as a whole, where the gender proportions for a similar distribution of ages are 65% and 35% respectively[49];
- The majority (41%) were aged in their 80's at the time of the research; 32% were younger than 80 (the youngest was aged 60) and 27% were 90 or older (the oldest being aged 100);
- 24 participants (38%) had been diagnosed with dementia, or another cognitive impairment – although this proportion was much higher among female participants (48%) than among male participants (22%);
- A small ethnic minority was represented in the sample, with 1 participant being of Caribbean ethnicity, and 3 participants of non-British, European ethnicity.

Six, core findings emerged from a cross cutting analysis of the detailed findings relating to each round of fieldwork. These findings apply equally to older people with high support needs living in care homes and those living in their own homes at risk of moving into care.

i. 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 participating in the research wanted the opportunity to 'live a normal life': to be part of daily routines many of us take for granted and to contribute to the community and

[49] Based on 2001 census data for South East England, http://www.statistics.gov.uk/census2001/pyramids/pages/j.asp

society they live in. Three specific features of this finding are highlighted in the main research report, including:

- The importance of contact with peers and other generations
- Handling money
- Keeping physically fit and healthy

ii. Maintaining an individual identity

A dominant theme throughout the research was that older people with high support needs are individuals, with unique experiences and histories that have shaped their lives and 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. As a research team we found it was not difficult to find out about people's identities - who they are and what is important to them - although there was evidence that this was not happening as a rule. One care staff member, when she heard about one woman's love of painting, was astonished that she had not known this about her, in spite of being involved in her care for some time.

iii. Belonging

A further common finding was older people's need to belong to personal networks that are meaningful to them; to contribute to interests and activities outside their homes; and to be a part of family and community life. For people living in their own homes, the presence of informal support networks was a key factor to them remaining in their own home. Many of the people we met told us they were either living in care homes away from their familiar locality, or they were no longer part of local community or family life.

iv. Aspirations and hopes for the future

Some participants had very clear hopes and aspirations for their current and future lives, although at times they were reticent to express them. These aspirations covered a wide spectrum of interests, activities and relationships. Many people we spoke to had wishes that they did not expect to see fulfilled, although it did

not take away the desire or need to hope and look to the future; and for some of our interviewees it was painful to talk about lost dreams.

v. Permission and Power

This finding focuses on the question of who holds the balance of power in relationships with or involving older people with high support needs? It highlights the precariousness and uncertainties of many people's situations, including not knowing what the rules are or who makes the rules when you live in a group situation. Similar feelings were shared, although less frequently, by those living at home. One man commented ruefully on the 'inevitability' of his loss of privacy and feeling of control over his own home as "too many people have access" (he was referring to people's knowledge of his key code). One of the main issues which emerged from this analysis was the distinction people drew between being 'cared for' and being 'cared about'.

vi. Choice and Control over Finances

The sixth finding, choice and control over personal finances, links strongly to people's feelings of personal authority and control, and whether they felt they had a voice or choice in the way their lives were run. It was a dominant theme in the care home and community interviews. The amount of control people had over their finances was very varied. We met care home residents (the majority of whom were men) who were in full control of their finances, suggesting a gender difference in roles within this particular generation. This also challenges popular stereotypes of older people with high support needs who are often considered unable to manage or control their own, often complex, financial arrangements. All those interviewed who were living at home had access to money /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.

Five overarching messages were identified from looking across these findings and identifying the dominant, emerging themes.

Firstly, it is evident that older people with high support needs wish to live a 'normal life', including contact with friends, family members, people of all generations in local neighbourhoods, and being a part of social networks. The older people we met have aspirations, and for some people, a strong sense of longing to be a part of the everyday activities associated with having a 'normal life' with opportunities for maintaining a healthy, active lifestyle. In spite of these clear aspirations, there is a very low set of expectations among the current generation of older people with high support needs with regards to their right to a good life with choice and control over their own personal support. This was clearly influenced by the predominantly low expectations and aspirations found amongst the different people who were in touch with or 'caring for' the people we met, including family members, care staff, neighbours.

Second, isolation and loneliness remains a significant issue[50] for older people with high support needs - both for those living in care homes and those living at home. Loss of (and lack of contact with) peers (both relatives and friends) reduces people's social networks in later life; we met many older people whose relatives and friends had either died and/or no longer kept contact with them. There was also isolation from familiar places including people's homes, local facilities and community activities, which all added to a sense of disconnection from community and daily life.

Third, people of all ages and stages of life have different life histories and different experiences – but the importance of older people's histories and life experiences cannot be overstated for

[50] Age UK Oxfordshire (2011) Safeguarding the convoy: a call to action from the Campaign to End Loneliness; Victor, C, Bond, J, Scambler, S (2009) The Social World of Older People Open University Press, Maidenhead; Victor, CR, Scambler, SJ, Bowling, A and Bond J. (2005) The prevalence, of, and risk factors for, loneliness in later life: a survey of older people in Great Britain, Ageing and Society, 25 (3), pp357-76; Cattan, M. (2010) Preventing Social Isolation and Loneliness among Older People. Lambert Academic Publishing Saarbrucken; Department for Communities and Local Government (2006) Sure Start to Later Life: ending inequalities for older people. A social exclusion unit final report

those who need a lot of support in their lives. Professionals of all backgrounds, disciplines and levels (from care worker through to consultant physicians, housing tenancy officers to commissioning leads) need to focus their support and their services on engaging and listening much more closely to older people and the people in their lives, in order to get to know and really understand what's important to individuals as well as whole communities. This links to hearing people's stories and understanding the importance of life course for older people – how earlier life experiences may be impacting on people's lives, circumstances and choices now.

Fourth, knowledge and information, and support to use information tailored to individual needs and circumstances, is crucial for exercising voice, choice and control. We met a number of people who were struggling to find out about and access information that would enable them to retain control and make informed choices. A key message was the over-riding need for personal support to make sense of the wealth of information that does exist; and the need to trust the information giver and provider of that support.

Those workstreams that focused on this aspect of independent living had clearly understood the centrality of this issue in enabling older people with high support needs to exercise choice and control, and the steps they were taking to improve and adapt their provision was welcomed.

Finally, older people with high support needs feel powerless in many of the situations they find themselves, and this power differential with professionals and family often goes unrecognised and/or unacknowledged. This can be overcome by prioritising and strengthening mechanisms for older people to be equal partners in all aspects of decision making, and ensuring they are supported to find solutions to living their life in the way that makes sense to them. The focus on increasing the individual and collective voices of older people with high support needs within SERI has helped to shift attitudes at all levels of local service systems, in specific settings and within local communities, but our discussions with

individuals involved in this initiative have confirmed that this is the start of a very long journey.

In addition to these five messages, a number of important lessons are also highlighted in the full Findings report, sharing insights gained from the design and implementation of the research - with a view to informing both changes in practice and future research.

Clarity and familiarity with the research subject

The research team were aware from early planning stages through to interviews and conversations with research participants, that the research challenged a number of people. Specific lessons from undertaking the research include:

- The need to adapt language and provide examples in order for ‘independent living’ and ‘voice, choice and control’ to be meaningful to different participants, consultees and staff.
- The need to raise expectations about older people with high support needs (especially those living with dementia) being able to participate in research.

Focusing on unheard voices

Our commitment to communicating directly with the older person with high support needs in this study:

- Challenged some perceptions exposing embarrassment and low expectations of professionals, relatives, friends and neighbours
- Was aided and strengthened by the ethical approval processes
- Empowered older people, helping them to feel valued
- Was welcomed by families and carers, once it had been explained, who then worked with the research team to enable their friend or relative to have their voice heard

Including older people with dementia in research

We learnt a great deal about involving people living with dementia in research, including insights into how people's thoughts, views and experiences about complex issues can be gathered where communication is difficult. We found that expectations and attitudes were still firmly of the view that people with dementia either have nothing to offer the research process or cannot be engaged in any meaningful way. We also found that participants wanted to be involved, enjoyed the process and enhanced our understanding of their situations.

The need for flexibility in the design of research over time
Specific issues that require attention in the design and implementation of future research to ensure this is productive for everyone involved, include: how to establish and track changes over time when working with people living with dementia who may be living in different places and times; and accommodating participants' changes in health and circumstances, including patterns of communication and memory recall.

Repeat interviews and continuity

Participants often remembered us between research visits, which was very encouraging. This ranged from people having “some recollection” of us from previous visits, to people becoming familiar friends and inviting us round to tea. As one team member described, “Being remembered – and trusted – felt good”.
Involving consultees; families / friends / neighbours / carers
Involving a third party at times helped us to reach and hear the participant’s voice, although in some situations the consultee’s own voice dominated. In most cases, the role of family and friends as ‘proxy’ or additional voices for participants was invaluable. There were a few people where, despite our best efforts to communicate with the primary participant, the main interviewee became the carer. However this gave those carers a rare and valued opportunity to tell their own story and know that they, also, were being listened to.

Role modelling co-production in the research team

The research team consisted of 4 members with a rich mix of ages, knowledge, experience and perspectives. This team approach was built into the design of the research, and enabled:

- Interviews to be carried out by sensitive, experienced peers, leading to rich, insightful data
- Interviewers to work in pairs ensuring effective use of interview and participant time, consistency of approach and reliability of findings between team members.
- A learning environment where different perspectives were brought forward, providing rigorous challenge and debate.

Finally, the full Findings Report outlines three areas for action for improving the life chances and experiences of older people with high support needs, including:

i. Specific issues identified in the findings and key messages
ii. Lessons learnt from the design, methodology and experience of undertaking the research
iii. The use of data, research tools and resources developed for SERI.

Appendix 4 – Quantitative data collection and analysis

A range of quantitative and qualitative data was collected on the number and characteristics of older people with high support needs who were engaged, involved and supported in the seven SERI workstreams. The data was collected by the sites themselves, with support and guidance provided by NDTi and ODI staff.

The framework of indicators, data sets and sources used for this element of the SERI is summarised below.

Area of focus: Person Centred Approaches in Care Homes (all sites)

Outcomes and indicators:

- Individualised support for older people
- Embedding changed practice
- Outcomes for residents (happiness, satisfaction, greater choice & control, increased participation, other personal goals identified)
- Outcomes for families (satisfaction, happiness)

Who has this info?

- Mix of care homes, workstream lead in each site, LA & PCT in each area

How will data be reported?

- **Data type**
    - Nos and %'s drawn from PI data returns and CQC visit reports.
- Costs, incl unit costs where possible.
- Personal support plans
- **Time periods**
- Quarterly and annual data and trends for 2007-08, 2008-09, 2009-10 to date.

- **Data for…**
    - Participating care homes plus others in each site if available (i.e. trends)

Area of focus: Increasing voice (all sites)
Outcomes and indicators:

- Involvement/participation of older people with high support needs in SERI workstreams (Numbers of older people with high support needs involved in voice events; number/type of opportunities to have a voice; numbers involved in workstream activities)
- Mechanisms for ongoing participation established
- Increased involvement of older people with high support needs in ULOs, peer support groups, older people's forums (numbers involved in existing local fora/groups)

Who has this info?

- Site steering groups and NDTi change management team

How will data be reported?

- **Data type**
    - Figures & narrative.
    - Voice mapping exercises.
    - Figures & % groups whose membership includes older people with high support needs
- **Time periods**
    - 2007-08, 2008-09, 2009-10 to date
- **Data for…**
    - Whole site, localities for some workstreams (e.g. West Oxon, Drayton & Farlington, Worthing & Adur)

Area of focus: Transport information line (Oxon)
Outcomes and indicators:

- Better understanding/ knowledge about transport needs, options and gaps for older people with high support needs in rural areas
- Development of information on accessible transport and support
- Older people identifying needs, gaps and solutions
- More older disabled people able to get out and about
- Increased wellbeing and IL
- Increased access to community based support
- Reduced carer stress
- Reduced levels of isolation, depression, low mood
- Reduced admissions to care homes

Who has this info?

- Workstream group, site steering group, LA (dept of transport), transport adviser stats, transport providers, vol orgs and community groups, desk based research carried out by Oxon

How will data be reported?

- **Data type**
  - Trends and preferences in Oxon survey
  - Nos accessing transport adviser, solutions provided and follow up info
  - Examples of tailored solutions (and trends)
  - Nos accessing volunteer support and community groups
  - Nos reporting reduced stress
- **Time periods**
  - Monthly since service begins until end Sept 2010
- **Data for…**
  - West Oxon (where transport adviser service located) and Oxon as a whole wherever possible/relevant

Area of focus: Dementia information & advice line (Oxon)
Outcomes and indicators:

- Reduced levels of anxiety/low mood for people living with dementia and their carers
- Increased levels of early diagnosis/access to diagnostic tests
- Increased access to early intervention, advocacy and support including peer support/advice
- Increased access to PB's/SDS
- Reduced levels of stigma associated with dementia
- Increased GP awareness about IL, SDS, range of support options available/needed

Who has this info?

- Workstream group, site steering group, LA, PCT, GPs, vol orgs and support groups, volunteers, dementia advisers

How will data be reported?

- **Data type**
  - Reduced visits/reliance on GPs
  - PCT/NDS indicators
  - Diagnostic rates/visits to memory clinics
  - Take up of PB's/SDS
  - Take up of early interventions, advocacy and peer support
  - Change in awareness/ attitudes
- **Time periods**
  - Monthly since set up of service until end September 2010
- **Data for…**
  - County wide

Area of focus: Circles of support /neighbourhood approach (Portsmouth)

Outcomes and indicators:

- Better knowledge of local characteristics of older people with high support needs
- Shared vision of IL for older disabled people
- Better partnership working
- Ongoing mechanisms for older disabled people to participate in decision making individually, locally and across the city
- Increased access to range of services/support by older disabled people living at home in this area
- Less reliance on adult social care £ and support
- Increased access to info, advice and advocacy support
- Increased wellbeing and IL
- Reduced admissions to hospital
- Reduced admissions to care homes
- Reduced (inappropriate) contact with GPs

Who has this info?

- Workstream group, site steering group, change managers, LA, vol orgs, community groups, PCT

How will data be reported?

- **Data type**
    - Ward profile
    - Incr access to & take up of personal budgets
    - Nos accessing different transport options
    - Nos accessing benefits
    - Nos supported by social care
    - Nos accessing different kinds of info/advice /advocacy
    - Nos with circle of support
    - Nos with increased network in circle
    - Satisfaction rates with home and neighbourhood
    - Nos admitted to hospitals /care homes
    - Nos in contact with primary health care
- **Time periods**
    - One off by LA for D&F
    - NI data for D&F/city

        - Data collected through place survey
        - Data collected by LA, PCT, GPs
        - Info from work-stream group and CMT
    - **Data for…**
        - D&F and city

Area of focus: Information & advice on discharge (West Sussex)
Outcomes and indicators:

- Increased access to information and advice about community based support/services (post discharge)
- Increased access to wide range of community based support (especially third sector, ULO, peer support, self directed support)
- Increased wellbeing and independent living

Who has this info?

- Workstream group and site steering group
- LA and PCT
- Age UK West Sussex

How will data be reported?

- **Data type**
    - Nos referred to Age UK team from hospital depts.
    - Nos of these followed up/take up support
    - Trends post discharge (where people went, resources they accessed, what happened at 3/6/912 months?
    - Contact with other services
    - Take up of PBs
    - Reduced hospital readmissions
    - Reduced care home admissions
- **Time periods**
    - Monthly since service instigated to end Sept 10; quarterly for NI data 2007-08 to 2009-10, for whole of WS
- **Data for…**
    - Named hospital and catchment area covered
    - Trends for whole of WS

Area of focus: Regaining Independence and Support in Worthing, Adur, Littlehampton (West Sussex)
Outcomes and indicators:
Increased wellbeing for older people living in Worthing, Adur & Littlehampton who have recently been in hospital including:

- Service develops in response to older people's outcomes
- Reduced hospital admissions
- Rehab outcomes
- Admissions to hospital within 28 days of discharge
- Attendances at A&E within 28 days of discharge
- Attendances at GP surgeries within 28 days of discharge

Who has this info?

- Workstream group, site steering group, LA and PCT

How will data be reported?

- **Data type**
  - Analysis from WS research
  - Nos & anonymous case studies
  - Nos & % case where outcomes achieved
  - 90 day post discharge destination
  - Nos collected for NI
  - As it comes
- **Time periods**
  - One off, quarterly and annually
- **Data for…**
  - For named localities and WS as a whole wherever possible

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Web: www.odi.gov.uk
Post: Office for Disability Issues, Ground Floor, Caxton House, 6-12 Tothill Street, London, SW1H 9NA
Email: office-for-disability-issues@dwp.gsi.gov.uk
Telephone: 020 7340 4000

ISBN: 978-1-84947-579-2
Produced by the Office for Disability Issues, May, 2011