



“Working with smaller  
housing associations to  
create dementia friendly  
organisations”

David Hucker  
Trust Chairman  
January 2014



The small charity that makes a **big** difference.



## Introduction by our Patron

Once again I put pen to paper out of sheer pride at my association with this small, but imaginative and energetic charity.

In May 2012, we published the results of a major research project carried out with Age UK Warwickshire entitled: *"Housing and care for the most vulnerable older people. What can social housing providers and older people organisations do together?"*

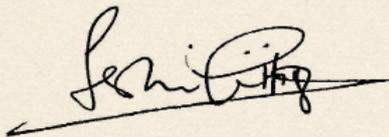
The project consisted of a programme of research and policy work using the format of 'Inquiry' and giving it a wide appeal. The research was based on the needs of older people with dementia, mental illness and selected health related problems and the different ways in which organisations could join forces to respond to those needs.

However, we saw the research outcomes as the beginning, not the end of the story and, in conjunction with Orbit Group, embarked on a follow-up project which aimed to provide support to smaller and non-specialist housing associations to help them develop effective services for older tenants, particularly those with dementia, to have a better quality of life living in their own home.

As with our first project, we wanted the research to have real and practical benefits, so are grateful to those associations that worked with us in an open and honest way so that we could all learn lessons to benefit those who need and depend on our services.

Also, we are pleased to signpost some of the services provided by the Alzheimer's Society, which we hope associations will find useful.

I commend this report to you.



The Reverend the Lord Griffiths of Pembrey and Burry Port Trust Patron January 2014





# About us

1. We are a company limited by guarantee and started life in 1989 as the Orbit Housing Charitable Trust Limited. We became a registered charity at the beginning of 1990, subsequently shortening our name to Orbit Charitable Trust (OCT).
2. We are committed to helping and supporting vulnerable people to establish and sustain their well-being and quality of life. We do this by working with our partners, by building confidence in those we support and by accessing resources that can facilitate lasting change.
3. The objects of the Trust were revised as part of a new, updated Articles of Association adopted at an Extraordinary General Meeting on 1 June 2012. They include, but are not limited to:
  - The provision of financial and other support to charitable and other organisations and individuals to relieve poverty and hardship
  - Relieve elderly people in need
  - Develop the capacity and skills of members of the socially and economically disadvantaged
  - Relieve sickness and promote the preservation of health of persons suffering from mental or physical illness
  - Relieve unemployment
  - Advance in life, and relieve the needs of, young people.

## Background to the Project

4. In late 2010, the Trust, in conjunction with Age UK Warwickshire, engaged Riseborough Research & Consultancy Associates to carry out a research project entitled: "Housing and care for the most vulnerable older people. What can social housing providers and older people organisations do together?"
5. The project consisted of a programme of research and policy work using the format of 'Inquiry' and giving it a wide appeal. The research was based on the needs of older people with dementia, mental illness and selected health related problems and the different ways in which organisations could join forces to respond to those needs.
6. One of the key outcomes was to show how organisations can change their ways of delivering service by putting the customer at the heart through person centred working. We believe there are three main reasons why housing associations and older people's organisations should consider what the project had to say:
  - Person centred working makes ethical and business sense. There is the capacity to make the public pound and social investment go further but, make no mistake, doing person centred working is not what all customers want
  - Person centred working is not possible without full scale organisational change to support and drive it. The changes have to incorporate changes in staff and volunteers' personal practice
  - All person centred changes don't have to cost the earth. Small changes that cost little or nothing are highly effective.

7. However, we saw the research outcomes as the beginning, not the end of the story and, in conjunction with Orbit Group, embarked on a follow-up project which aimed to provide support to smaller and non-specialist housing associations to help them develop effective services for older tenants, particularly those suffering from dementia, to have a better quality of life living in their own home.

## The Concept

8. Our original research explored the role of social housing providers in terms of supporting vulnerable older people and highlighted the need to enhance their partnerships and communication mechanisms with other providers. The research identified that:
  - In order to ensure older people are supported to remain within the community and at home, social housing providers need to develop interventions and relationships with other relevant partners to ensure older tenants living with a diagnosis of dementia are supported effectively.
  - They also need to ensure staff are trained and supported to meet the challenges posed by dementia and how older people affected can be supported to age in their own home for as long as possible.
9. Regrettably, many social housing providers have still not got to grips with the fact that older people underpin their business and, for many, provide over 50% of their residents. Housing providers should see older people as core business across their work, whereas many see older people just as customers of sheltered housing.
10. All providers should have a business support role for some of the community organisations in the areas where they operate and be clear of the changing needs of the customer. Social landlords whose aspiration is to offer a home for life need to ensure staff and tenants are informed of and supported in accessing appropriate advice, information and support, especially in relation to living with dementia.
11. There is a role for outreach work by housing organisations to support the wider population of older people and not just those currently living in social housing.
12. The project, which was supported by the National Housing Federation, Chartered Institute of Housing and Housing Learning and Improvement Network, was carried out over a period of 15 months from October 2012 to December 2013.

## National Context

13. In 2012 the Prime Minister issued a challenge inviting society and all interested organisations to consider how the lives of people with dementia can be improved. A programme of work was announced as a result by the Department of Health. The report “Dementia 2012 A National Challenge”, produced by the National Alzheimer’s Society in 2012 was one of the early Challenge responses and presented vivid details, facts and figures about the lives of people with dementia and their families.
14. The need for massive improvements was laid out in detailed recommendations and suggestions including building up evidence based bank of research and practice on what works well to enable people with dementia to have better lives.

15. There are 800,000 people with dementia in the UK today with numbers set to rise to over one million by 2021. It is estimated this will reach 1.7 million by 2050. One in three people over 65 will die with a dementia, and it is thought that more than 60 per cent of all care home residents aged over 65 have a form of dementia. Dementia **is not** a normal part of the ageing process. Nor is it only a condition of older age. There are over 17,000 people under 65 with dementia in the UK. However, having an ageing population brings with it an increase in the incidence of dementia of one type or another.
16. Some commentators estimate that dementia will cost the UK over £23 billion in 2012, and this figure will rise to £27 billion per annum by 2018. Unpaid carers supporting someone with dementia save the economy £8 billion a year. Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke.

## Our Approach

17. A 2012 survey by the Scottish Chartered Institute of Housing and the Joint Improvement Team (NHS Scotland) discovered that most housing organisations are getting better at understanding dementia friendly design, some are applying the principles to their specialist accommodation and some organisations intend to do so in the future. A number of housing organisations are also joining with local planners and others to improve the design of neighbourhoods so that they are age friendly and inclusive for people with dementia.
18. Since most people with dementia live in ordinary housing in the community any improvements are likely to be beneficial. At an operational level many housing organisations recognise the need to ensure that staff have the skills set required to deal with current and expected challenges. Some organisations are training their front line staff in dementia awareness. All organisations work in partnership with social care.
19. However, the same survey shows that many organisations are not prepared fully to deal with the challenges facing them and only some organisations have done any of the above consistently as part of a long term improvement plan. The impact of the ageing population, coupled with the prevalence of dementia, cannot be underestimated and housing providers now face a real challenge in ensuring they can offer older people the real choice of a "Home for Life" and reduce the number of times a person has to move.
20. The reality for many social housing providers is that they will be not be aware of the percentage of residents who have an early onset of dementia and this project set out to identify the issues and work with organisations to address the many challenges posed for the person with dementia, other tenants and staff.
21. Our aim was to provide support to smaller and non-specialist housing associations to help them develop an effective response to support tenants suffering from dementia to have a better quality of life living in their own home.
22. Unlike larger or specialist providers, smaller housing associations and almshouse trusts with, say, up to 1,000 properties in management, are unlikely to have the resources and knowledge to identify and address problems encountered by aging tenants in their properties.

23. The project involved five stages, namely:

- London pilot group
- National baseline survey
- Learning event
- Demonstration projects
- Good practice guide

## National Baseline Survey

24. We planned to gather information about how well prepared small housing associations are to face the challenges of developing services to meet the needs of an aging client group through a short online questionnaire. Based on the findings, we would then work closely with a number of organisations as demonstration projects following the lines of the original research.

25. Before sending the questionnaire to a wider audience, we tested it on nine London-based organisations and met with them on 24 October 2012 to discuss the results and any changes needed to the format. We are indebted to the following for their help.

<b>Name</b>	<b>Organisation</b>
Vivienne Astall	Keniston
John Castleberg	Kingston Churches
Ziggy Crawford	Barnsbury
Helena Deacons	Crown Housing
Marianne Duffield	Womens Pioneer
John Delahunty	Innisfree
Linda Milton	Waltham Forest
Gina Tanoh	Walterton and Elgin
Phyllis Osie	
Chris Turton	Sutton Housing

26. Our starting point for the new research was a baseline survey carried out in June and July. In all, 88 organisations responded out of 294 emailed, a response rate of 30%. Some of the headlines are:

- The clear majority of respondents classified themselves as generic housing associations, catering mainly for general needs (60%). Just under a third represented themselves as specialist housing associations (32%). No organisation classified itself as an almshouse
- Just over half of those responding had stock sizes under 1,000 properties (51%). The remaining 49% had over 1,000 properties. The largest response came from housing associations with between 1,001 and 5,000 properties (21.5% overall)
- The majority of respondents do not have an Older People's Strategy in place (48%). A lesser, but still significant proportion – nearly three in ten – do have such a strategy (28%)
- Whilst a quarter of those without an Older People's Strategy have plans, or already in the process of developing one, 59% of those without a Strategy indicated that they did not intend to draw one up

- Only 8% of all respondents have a Dementia Strategy in place. Of those without such a Strategy, around a quarter have plans to develop one; but almost a half said they either did not see the need for one or had not yet thought about it
  - Nearly four in ten organisations (38%) have plans for developing or consolidating services for older people. Respondents spoke of extending the types of services they provide for existing tenants; rolling services out into the wider geographical community; and/or engaging with new groups. Others spoke of consolidating existing services under one umbrella or developing a 'one-stop shop' approach.
27. The survey highlighted that the overall level of awareness of dementia needed to be improved among housing providers. The challenge for us was to use the findings in a pro-active way to help housing organisations build a strategy to adapt and develop ways of supporting dementia sufferers.

## Learning Event

28. Following the approach successfully adopted in the first research of working with organisations to evolve demonstration projects, we planned to involve associations chosen to reflect a diversity of communities taking into account:
- Geography
  - Economics
  - Cultural diversity
29. A number of respondents said as part of their survey return that they would be willing to work with us further and to attend an event. Fourteen people participated in a day-long facilitated workshop led by Moyra Riseborough on 30 September 2013 representing the following organisations:
- Endeavour Housing Association
  - Heantun Housing Association
  - Inisfree Housing Association
  - IDS
  - Racing Homes
  - Sutton Housing Trust
  - Waltham Forest Housing Association
  - Women's Pioneer Housing
30. Participants spoke with pride and enthusiasm about the work they are doing to support people suffering from dementia and we are grateful to Jeremy Porteus, Director of the Housing Learning and Improvement Network, and Esther Watts, Dementia Action Alliance Co-ordinator for London and the South East, for their contributions to a successful day.
31. We chose as the theme **creating dementia friendly organisations**, with our aim being to help associations improve their capacity to work better with individuals and their families to cope with dementia. We wanted to tease out just what is happening now, examples of good practice and where the gaps are.

32. Some areas that we wanted to cover in the demonstration projects are:
- A number of associations have links with organisations such as Age UK, but just how do these help shape and deliver services?
  - How are customers actively engaged and how do organisations change the way they deliver services to make them truly person-centred?
  - Where does responsibility lie within the organisation to ensure that policy, practice and training reflect the needs of sufferers?
33. There are no guaranteed blueprints that will produce the definitive dementia friendly organisation, but there is a growing body of useful and practical evidence including check lists and emerging good practice that should be taken on board.
34. There is helpful guidance in the campaign launched by the Alzheimer's Society and the Dementia Action Alliance to encourage organisations to become dementia friendly communities. Working through scenarios designed for the event and checklists, the participants shared their current practice, considered alternative ways to deliver their services and actively apply learning points from the workshop to their organisations.
35. The evidence the workshop drew on included the World Health Organisation's Global *Age Friendly Cities* network (2007) including a Guide; evidence from research for the Joseph Rowntree Foundation *Creating a Dementia Friendly York* (2012), publications from the Foundations Better Life in Later Life programme on dementia including publications involving people who have dementia and, research by Innovations in Dementia to build dementia friendly communities<sup>1</sup>.
36. Also, the workshop used Viewpoints commissioned by the Housing Learning and Improvement Network, see for example *Breaking New Ground: The Quest for Dementia Friendly Communities* by Dr Lynne Mitchell (June 2012).
37. To get the most out of the workshop, participants were asked to do some preparatory work and read a short briefing paper. They were also asked to provide some examples of practice in their organisations and answer three questions:
- What does your organisation do to assist people with dementia and their families now?
  - Where does your organisation want to get to?
  - What you want to take away from today?
38. At the end, participants had started to draw up an action plan to improve practice and procedures in their organisations.

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<sup>1</sup> Report on creating dementia friendly communities. Innovations in Dementia 2012.

39. Feedback on the workshop is appended to this report, but the key points emerging were:
- Even if an organisation doesn't have a dementia strategy it can take a range of actions that move it towards being a dementia friendly action
  - There is some good practice that small housing associations and, indeed, other organisations, can share – it's a matter of promoting it
  - Small housing associations often know more about their tenants than do larger associations
  - Providers must not concentrate on those living in specialist accommodation to the exclusion of those living in the wider community
  - Within and, indeed, between organisations knowledge can be transferred from those working in sheltered accommodation to those working outside
  - If organisations are to become dementia friendly there is a need for a whole organisation, non-compartmentalised approach
  - Being dementia friendly is an on-going process
  - Dementia friendly work needs to become part of day-to-day work – it should be normalised, not compartmentalised

## Planning for the Future

40. Not surprisingly, associations were looking for help in developing a strategy for supporting people with dementia and gearing up their organisations to provide the right services. We have provided a quick guide on what a strategy should look like.
41. We are grateful to Orbit Group for allowing us to include in this report a piece of work which we carried out for them titled "Laying the foundations for living well with dementia."
42. Although centred around one of the Group's subsidiaries, Orbit Heart of England, the approach and methodology form a good basis for all associations looking to move forward. The executive summary provides a step-by-step guide to how existing services can be reviewed and how to plan for the future, with particular emphasis on people with dementia.
- An analysis of current profile of dementia issues and needs within each scheme, using hard and soft data sources, a map and an analysis of current community and statutory provision for dementia in each locality.
  - A skills audit and training needs analysis of relevant team members, management and supervisory structures.
  - Consultation with stakeholder groups to identify issues, perceptions, experiences, gaps in services and future concerns.
  - Development of a training resource to enable workforce and individual development and awareness raising.
  - The delivery of training and workforce development on dementia including supervisory structures, skills sharing and training needs recording.
  - Exploration of assistive technology and future needs for current schemes not as an 'add on' service but a key part of everyday life.

- Exploration of tele-healthcare solutions to tenants including an examination of the infrastructure required for a successful tele-healthcare scheme and the need to measure the impact of tele-healthcare solutions. This will provide an evidence base of its benefits to enable further development of these kinds of services based on the cost saving impact for housing sector and on other arenas such as health and social care as well as the improved quality of life for the user.
- Produce a 3 year Dementia Strategy.

## What happens next?

43. The small housing associations participating in the workshop were keen to develop their services and willing to share their good practice and improvement plans for improvement. A number are becoming members of their local National Dementia Alliances or will start some new local ones. One small workshop has, therefore, led to a potential series of changes.
44. Associations are keen to stay in touch and we have asked Moyra Riseborough to keep a watching brief to monitor their development in transforming into dementia friendly organisations. In addition, Moyra will be working with three or four organisations to produce case studies, covering a range of initiatives.
  - Innisfree and Waltham Forest are both engaged in reminiscence work. In the case of Innisfree, which works with the Irish community in London, it will tell us how this can be made culturally specific. Each organisation is also at different points in their learning journey, but they often work together.
  - Racing Homes work also relates to a particular community based on a common background and they are at the start of a journey.
  - Heantun in Wolverhampton because it is located within a city that has signed up to being dementia friendly and the organisation has made the most significant progress of all.
45. By maintaining communication with all the small housing associations, we can track how they took up the challenge of being involved in local National Dementia Alliances following the learning event. The involvement could give them the relationships they are seeking with key decision makers and commissioners in health and social care. It would be interesting to follow their experiences up to see if the relationships prove helpful to their work.
46. We plan to hold a further workshop to round off the sharing practice and ideas with small housing associations in Autumn 2014.
47. To keep in touch with the project, please go to our website: [www.orbit-research.org.uk](http://www.orbit-research.org.uk)

# Appendices

National Baseline Survey Results

What People Said About The Survey Results

Outcomes Of The Learning Day

- Becoming Dementia Friendly
- Check List

Developing A Dementia Strategy – A Quick Guide

Laying The Foundations For Living Well With Dementia

The Alzheimer's Society





# Small Housing Associations Research

## Survey Report

June - July 2013



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# Executive Summary

## Purpose of the report

This report presents the findings of a survey about the Older People Strategies of smaller and specialist housing providers carried out during June and July 2013. Of 294 organisations mailed, 88 responded, representing a response rate overall was 30%. This is considered a good response for a survey of this type.

The mailing was based on two contact lists provided by the National Housing Federation covering Care and Support Housing Managers and organisations providing housing for older people. Some of the responses were, therefore, from associations outside of our original target audience, but they have been included in the overall results as adding to the picture of where organisations have reached in their thinking.

## Key findings

### 1. About the respondents

The clear majority of respondents classified themselves as generic housing associations, catering mainly for general needs (60%). Just under a third represented themselves as specialist housing associations (32%). No organisation classified itself as an almshouse.

Just over half of those responding had stock sizes under 1,000 properties (51%). The remaining 49% had over 1,000 properties. The largest response came from housing associations with between 1,001 and 5,000 properties (21.5% overall).

Smaller organisations were more likely to be specialist housing providers, while larger organisations were more likely to classify themselves as generic housing providers.

When asked for data on the ages of their tenant populations, by far the largest percentage indicated that their tenants fell into the 66+ age category. The remainder of responses were split relatively equally between the lower age bands.

Nearly half of all responding organisations (48%) deliver services to older people through specialist, in-house teams. 14% stated that they deliver services to older people via a third party or external organisation. However, there is a small amount of overlap: around 6% use a combination of in-house and external service delivery.

### 2. Current practice and future plans

The majority of respondents do not have an Older People's strategy in place (48%). A lesser, but still significant proportion – nearly three in ten - do have such a strategy (28%).

A quarter of those without an Older People's strategy have plans or already in the process of developing one. However, 59% of those without a strategy indicated that they did not intend to draw one up.

Only 8% of all respondents have a Dementia strategy in place. Of those without such a strategy, around a quarter have plans to develop one; but almost a half said they either did not see the need for one or had not yet thought about it. Other reasons why organisations would not develop one included the size of the organisation; or the fact that it is already covered by other strategies which are in place.

Nearly four in ten organisations (38%) have plans for developing or consolidating services for older people. Respondents spoke of extending the types of services they provide for existing tenants; rolling services out into the wider geographical community; and/or engaging with new groups. Others spoke of consolidating existing services under one umbrella or developing a 'one-stop shop' approach.

### 3. Engaging with older people

The clear majority of respondents use one or more tailored approaches for delivering services to older residents. Most will use a combination of approaches, demonstrating a willingness to increase accessibility. Half of all organisations responding provide sheltered housing. Other common methods include large-print publications and loops.

More than half of all organisations (55%) enable residents to shape service delivery by consulting them on strategies and policies. 44% engage residents on decision-making committees. Most respondents use a combination of methods to try to ensure that all who wish to engage in shaping service delivery are able to do so.

Individualised support is the most commonly used person-centred practice by these organisations (41%); closely followed by resident-made appointments (40%). One in three (33%) also provide options for service delivery.

### 4. Partnership working and looking ahead

Age UK and the National Housing Federation are the two organisations that most of the respondents work with to inform service delivery to older residents: 35% of respondents reported partnership working with each of these. The Chartered Institute of Housing was another notable partner, for 24% of all respondents followed by the Housing LIN. A range of other partners, both local and national, were flagged up.

Nearly four in ten organisations draw on resources from The National Housing Federation. The Chartered Institute of Housing (33%) and Age UK (31%) were again cited by respondents as a source of information and guidance.

Only nine responding organisations were aware of the Orbit Charitable Trust resource pack. However, there appears to be a strong interest in Orbit's future research work: 40% of respondents would be interested in attending a future event and nine volunteered an interest in being a case study in the future.

## Conclusions

There are a greater number of generic housing associations than specialist ones. Specialist housing associations tend to be smaller in terms of housing stock.

Although a large number have many residents over the age of 66, only 28% of organisations surveyed have a specific Older People's Strategy in place; and only 8% have a specific Dementia Strategy in place (although many of these will make provision for those with dementia through existing strategies). Large percentages of respondents do not intend to develop either; often cited reasons are a lack of resources or because such strategies are not applicable to their tenant profile.

The clear majority of respondents demonstrate that they are keen to engage with older residents in developing and delivering services.

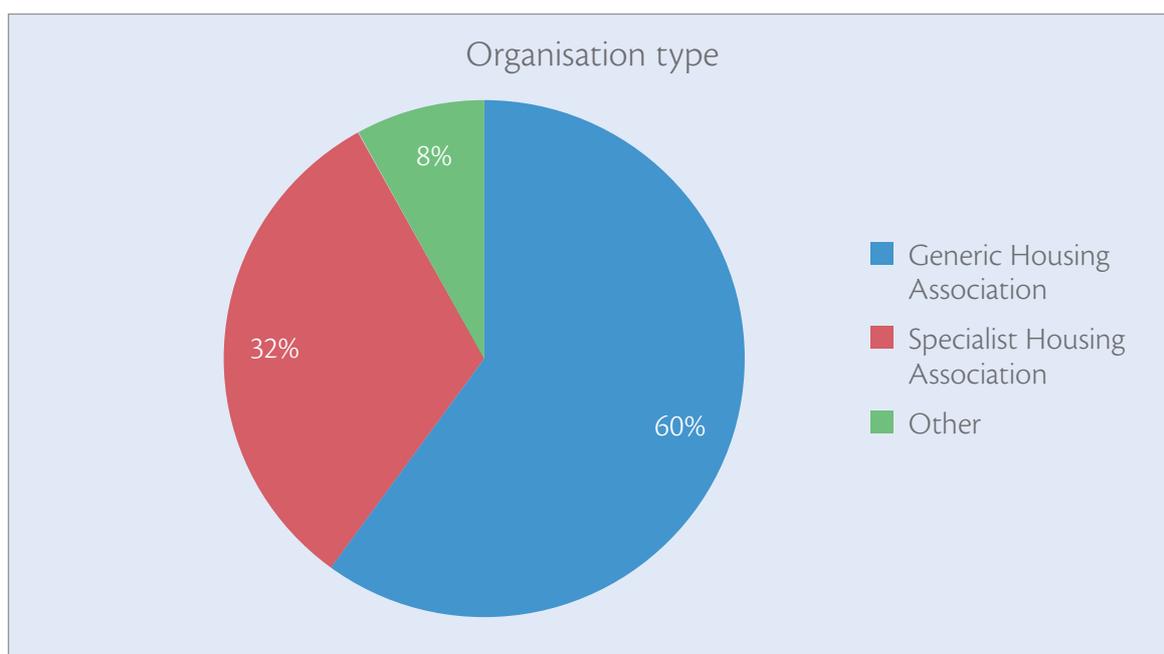
There is interest in contributing to future research through attendance at events or by being a case study. Far more people would attend an event than volunteer to be a case study, which may suggest that respondents are keen to raise their awareness of service provision to older people.

However, further action may be needed to raise awareness of Orbit Charitable Trust's resource pack.

## Section 1: About the respondents

### What is your organisation type?

Of the 88 organisations responding to the survey, the clear majority classified themselves as a generic housing association, catering mainly for general needs (60%). Just under a third stated that they represented a specialist housing association, providing services for designated groups of people (32%).



Seven organisations (9% of respondents) said that they fell into the 'other' category. Responses in this group included:

- Ex-RAF/ WRAF Personnel
- Some sheltered
- Mix of generic and specialist
- General needs plus support to 2,500 people
- 50-50 general needs and supported housing for a range of groups, including older people
- Both generic and specialist
- Sheltered housing - over 60s independent living.

Effectively, two of these could be re-categorised as specialist organisations (Ex-RAF/ WRAF Personnel and Over 60s independent living), while the remaining five could be classed as providing mixed services, ie both generic and specialist. Of these five, only one was a 'small' housing association, with between 251-500 properties; the other four each had over 1,000 properties.

No respondent reported that their organisation was an almshouse. It may be interesting to explore whether any are in fact almshouses but choose not to use the term.

## What is the stock size of your organisation?

Seventy eight out of the 88 respondents gave an answer to this question. It is interesting that nearly half of these (49% of those responding) fell outside of the four smaller stock size bands, having more than 1,000 properties. In order to give a more accurate picture, the data was broken down into a further three bands, 1,001-5,000; 5,001-10,000 and 10,000+.

Tables for the original and the revised bandings are below. Taking into account all seven bands, the greatest proportion of responses came from organisations with stock sizes between 1,001 and 5,000 (21.5%); followed by those with less than 100 properties (17%).



	Numbers responding	% of overall response
Less than 100	15	17%
101 - 250	8	9%
251 - 500	7	8%
501 - 1,000	10	11%
Other	38	43%
No response	10	11%

One person did not give a figure, stating that their organisation was simply 'a managing agent'.

The remaining 38 responses in the 'Other' category breaks down as follows:

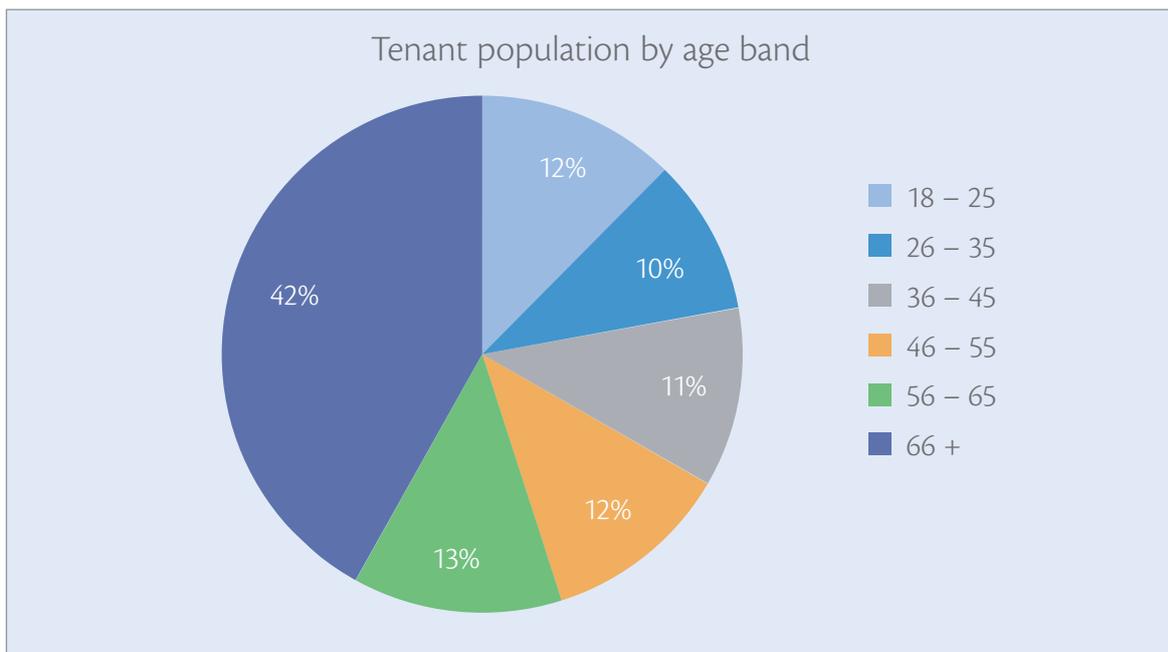
	Numbers responding	% of overall response
1,001 - 5,000	19	21.5%
5,001- 10,000	10	11.5%
10,001 +	9	10%

Looking at the proportions of generic, specialist and other by stock size, 78 respondents gave answers to both questions. The table below shows the distribution of housing association type by stock size:

	<b>Generic</b> (numbers responding)	<b>Specialist</b> (numbers responding)	<b>Other</b> (numbers responding)
Less than 100	2	11	2
101 – 250	3	5	0
251 – 500	1	5	1
501 – 1,000	7	2	0
1,001 – 5,000	14	2	3
5,001 – 10,000	9	1	1
10,001 +	9	0	0
<b>TOTAL</b>	<b>45</b>	<b>26</b>	<b>7</b>

This confirms that the smaller the organisation, the more likely it is to provide specialist services, providing services for designated groups. Conversely, the larger the organisations, the more likely it is to provide generic services.

**Roughly what proportion of your tenant population falls into each of the following age bands?  
Ideally, the figures you enter should total 100%<sup>1</sup>**



Thirty six organisations provided complete data on this question (41% of the overall response).

Although actual numbers responding were small, the aggregated percentages for all age bands show that by far the greatest proportion of these 25 organisations’ residents fall into the 66+ age category (42%).

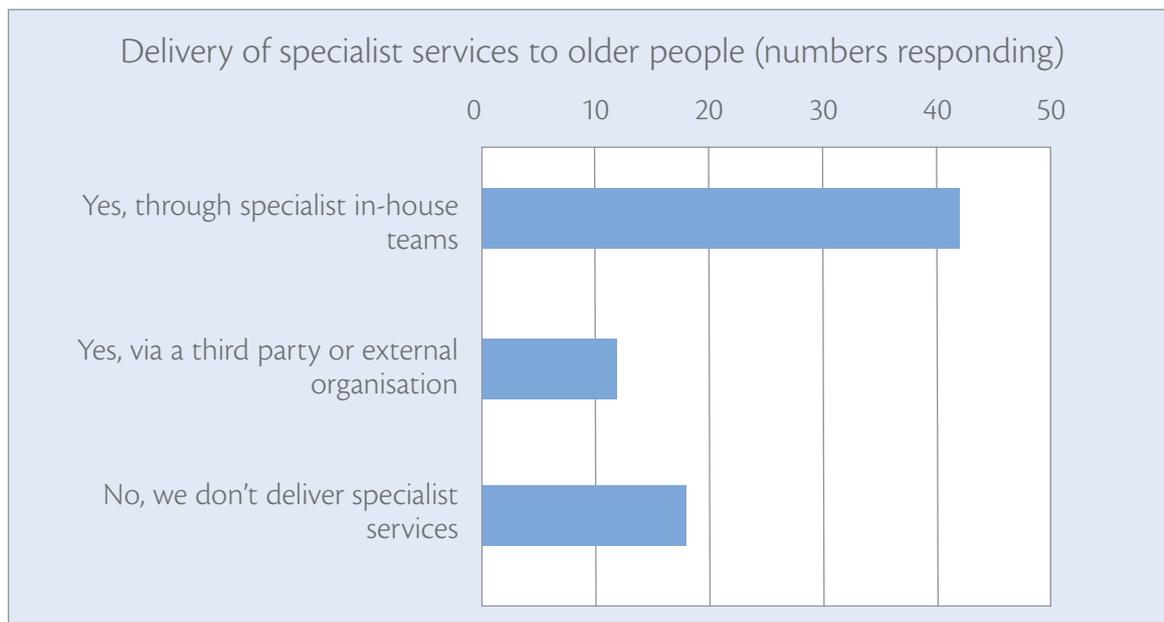
The next highest percentage was the 18-25 age band: 13.3% of the responding organisations’ residents fall within this age band. This was closely followed by the 56-65 age category (12.4%).

Thereafter, percentages for the remaining age bands were lower:

- 11.4% into the 36-45 age band
- 11.2% fell into the 46-55 age band
- 9.4% into the 26-35 age band.

<sup>1</sup> Percentages of responses don't add up to 100% due to rounding.

## Do you deliver specialist services to older people?



20% of all respondents to the survey (n=18) stated that their organisation does not deliver specialist services to older people.

48% of all respondents to the survey (n=42) stated that they deliver services to older people through specialist, in-house teams; and 14% of all respondents to the survey (n=12) stated that they deliver services via third party or external organisations.

However, there is some overlap: of these, just under half responded that services were delivered in-house and named organisations that provide external delivery.

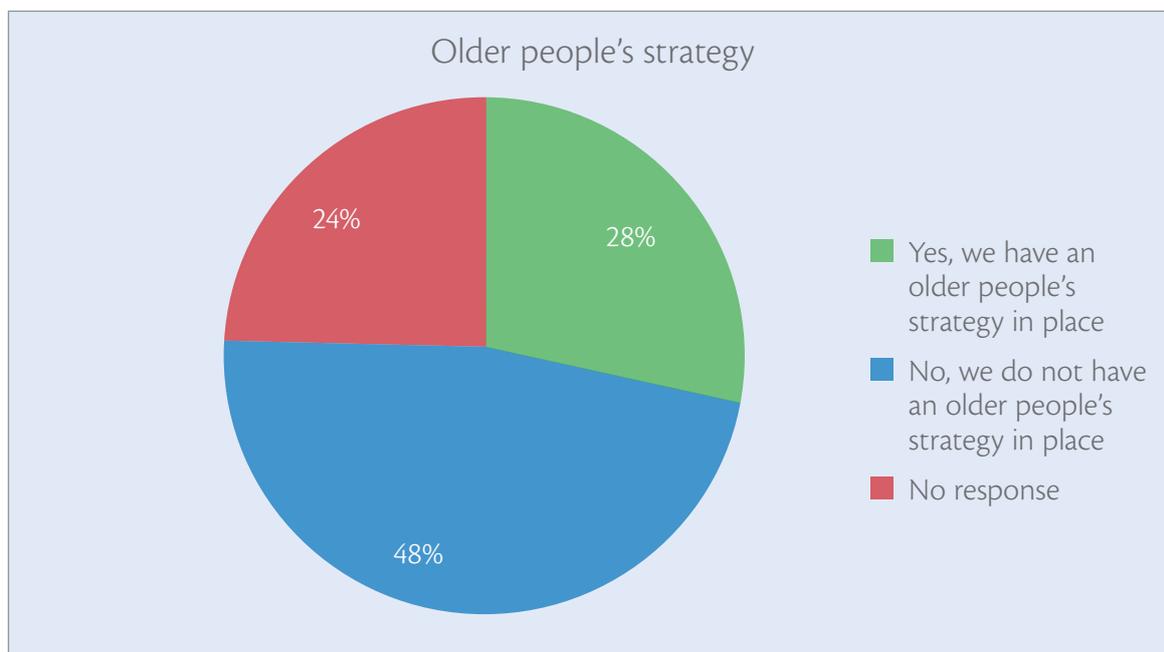
The responses given for organisations cited as external partners in the delivery of services included:

- Heritage Healthcare;
- Chichester Careline;
- Crossroads Care;
- Many;
- Via organisations commissioned by Local Authorities;
- Yes to specialist services but not specifically for older people - our customers with Learning Disabilities are of all ages;
- Aragon Housing Association;
- Subsidiary company Coastline Care Ltd;
- ECT, Heritage Care and Shaw; and
- Hanover, One Housing and Outward.

## Section 2: Current practices and future plans

### Do you have an Older People's strategy in place?

When asked if they had an Older People's strategy in place, the majority (48%) said that they did not. 28% of respondents said that yes, they did have such a strategy in place. 24% of respondents chose not to answer this question.



### If you do not have an Older People's strategy in place, do you have plans to develop one?

Of the 39 respondents who answered this question, 10 said that they had plans to develop an Older People's strategy (26% of those responding to this question).

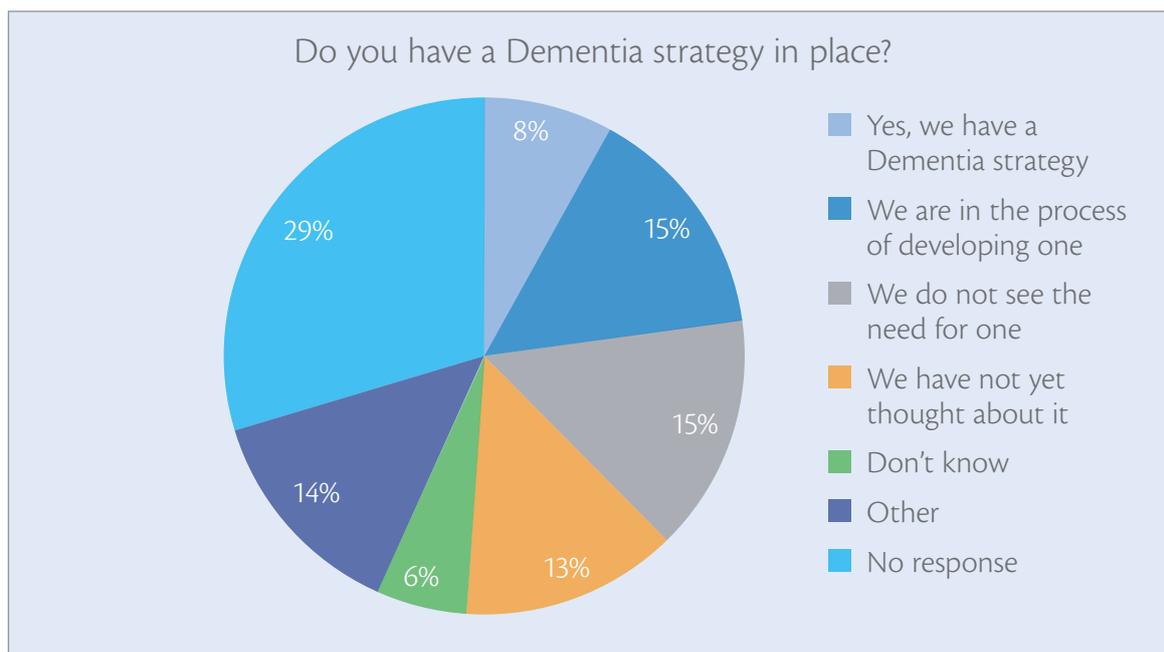
23 said that they did not intend to develop an Older People's strategy (59% of those responding to this question).

6 said that they did not know whether plans to develop such a strategy were in place (15% of those responding).

Although there were only a small number of comments from those stating that they did not already have an Older People's strategy in place, indications were that organisations were either considering the possibility or felt one was not necessary due to the nature of their customer base:

- "Possibly as part of our care and support and neighbourhoods strategies."
- "Not at present - our specialist group of customers all have a learning disability."
- "We specialise in Learning Disabilities."
- "We have development plans for older people's services."

## Do you have a Dementia strategy in place?



There were very low numbers of organisations reporting having a Dementia strategy in place. When asked, just 8% of all respondents (n=7) stated that they did.

- 63% of respondents (n=55) indicated that they do not have a Dementia strategy in place.
- 2% (n=2) said that they did not know.
- 27% (n=24) of respondents left this question blank.

## If you do not have a Dementia strategy in place, please tell us why

Of those 55 respondents who stated that they did not have a Dementia strategy in place, just under a quarter (n=13) reported that they were in the process of developing one. The same number (13) said that they did not see the need for one; while 12 organisations said that they had not yet thought about it.

Three individuals said that they did not know why one was not in place; and two declined to give a reason.

12 organisations added to their response by giving 'Other' verbatim reasons why they did or did not have a Dementia strategy in place. The majority of respondents indicated that the issue had been considered, but that (usually due to the size of the organisation) it was not considered necessary or desirable to have a separate strategy. Some organisations stated that they deal with cases on an individual basis; some that Dementia was dealt with under existing, overarching strategies. One stated that they used another organisation's strategy to guide them. These included:

- *"We do have this in place as we have different needs for our tenants, young families, single people and some elderly."*
- *"Although a strategy specifically for dementia is not in place our focus so far has been to engage and work with the local authority and other key partners in developing a strategic framework and understanding of the dementia agenda across the area."*
- *"We would not have a strategy for this purpose due to the size of our organisation, but the topic and our approach would be included in our policies and procedures."*

- “We intend to become a dementia friendly organisation.”
- “This forms part of our older person’s strategy - will consider developing separately.”
- “[We are a] very small organisation; deal on individual basis.”
- “This forms part of generic older people’s strategy at the moment.”
- “[We] use Worcestershire County Council’s strategy.”

Some had provided, or intended to provide specific training for staff on Dementia, to enable them to deal with tenants’ issues:

- “Staff attend awareness training.”
- “Training has been undertaken.”
- “We include issues such as dementia on our adaptations policy e.g. considering dementia friendly environments and we are also looking at dementia awareness training for housing officers.”

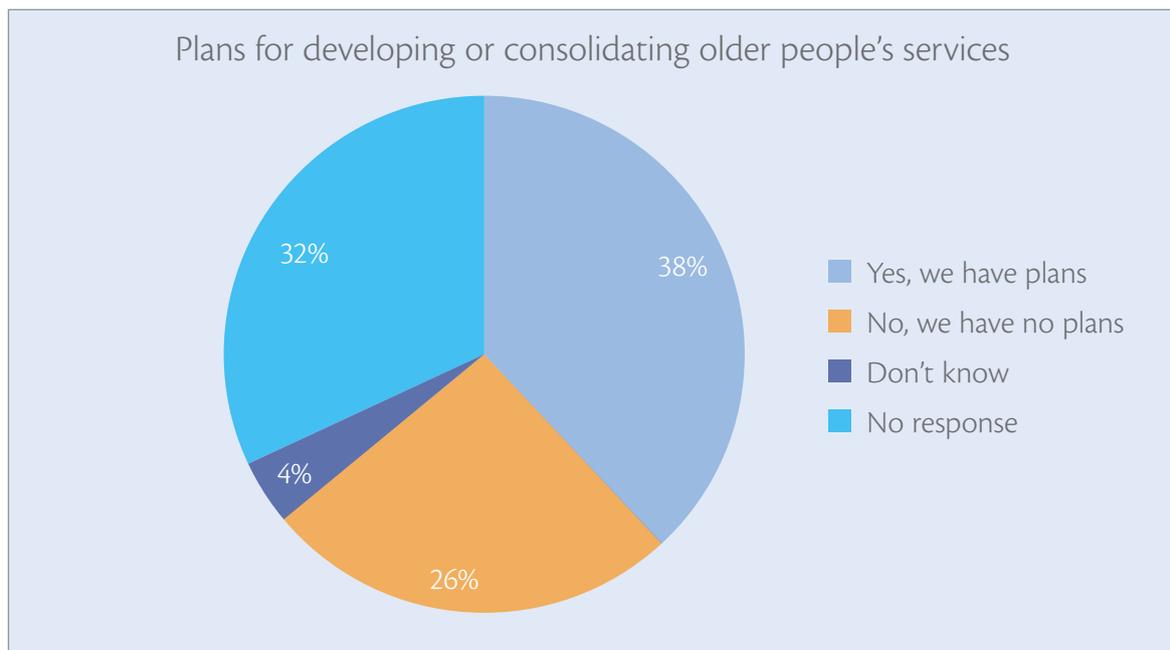
One indicated that such a strategy was not necessary as it was unlikely to be an issue for their specific tenant type:

- “[We are involved in] young person provision”

### Does your organisation have plans for developing or consolidating services for older people?

The largest proportion of respondents, 38% of the total response to the survey, indicated that they do have plans for developing or consolidating services for older people.

- 26% of respondents said that they didn’t have plans to develop or consolidate services for older people.
- 4% said they did not know whether such plans were in place.
- 32% gave no response to this question.



## Could you briefly outline your plans for developing or consolidating services for older people?

Many of the respondents' plans include developing or expanding accommodation and/ or services to older people

- *"We have aspirations to deliver additional units of retirement accommodation to meet the demands of our waiting list. This will be subject to raising the necessary capital funds and/or identifying a development partner."*
- *"Expanding Extra Care and community services for older people both in general needs and specialist housing. Digital inclusion strategy to include help & training for OP in ICT skills."*
- *"New nursing home and extra care development."*
- *"We are currently considering expanding our extra care services which currently involve management and support services to include care services either provided directly by us or a third party partner."*
- *"We currently have plans to re-develop our Residential Care home for older adults and hope to develop this extra care/ housing with care model to expand our delivery of specialist support services for older people."*

Several organisations spoke of moving into new areas – extending their services beyond social housing into the wider community; opening services up to new, designated groups of people; and working with other organisations to identify need:

- *"Moving to a floating support model and possibly expanding that to the community in the surrounding area."*
- *"We have been commissioned by Norfolk County Council to run a tenure-neutral community support service to older people in Norwich."*
- *"Expansion of services to the wider community. Bidding for alternative funding sources."*
- *"Offering our service outside of social housing to local communities where we have a support resource. Working with local GP's to identify referrals for support."*
- *"We are working with Federation of Irish Societies to develop strategies helping older Irish people to cope with dementia and other age related conditions which are more prevalent amongst the Irish community in the UK."*
- *"We are currently on the provider list with local County Council and are looking to move in to the care service."*
- *"We plan to make provision of leasehold for older people scheme."*

Several were in the process of consolidating services, whether because of funding issues; to provide customers with a 'one-stop shop' approach; or to tailor services better to individual needs:

- *"We are developing an integrated 'one-stop-shop' independent living service model aimed at (but not exclusively) older people offering access to assistive technology, handyman, personal care and practical and social support services. The service model is being developed in partnership with Heritage Healthcare."*
- *"We have recently consolidated all of our older persons' services under the 'supported' umbrella. Previously sheltered sat under general needs and extra care under supported. We have been working to consolidate and develop the team. Due to constant funding cuts we are now*

*reviewing the business model and are intending to work with an external consultant to consider a model appropriate to our service which is relatively small and hasn't the economies of scale that others can achieve."*

- *"Looking at consolidating Care & Support."*
- *"Launched the HH Foundation to develop a hub/spoke approach to providing services to tenants & the local community."*
- *"Our intention is to provide services that are better tailored to meet the needs of specific customers."*
- *"Integrating housing support, health prevention and care provision into a single management structure with shared aims, referral and flexible working practices."*
- *"Providing a MENU of services, modern housing developments, downsizing schemes."*
- *"We will develop a floating support service offering befriending small aids and adaptations, signposting. We are looking at developing new services-possibly helping them to move or transfer."*

A few specifically mentioned evaluating their housing stock to see if it meets current and future need:

- *"Looking at all stock to see if it is sustainable for the future and if stock needs to be decommissioned or services extended."*
- *"Developing accommodation to fit modern needs. Health and wellbeing strategies are being improved all the time."*
- *"We are seeking to develop more extra/flexi care homes, we are remodelling and updating existing homes and we have remodelled service provision and are seeking to consolidate these changes working with our residents to develop greater self-led support."*
- *"Increasing Demand and when we acquire Older People stock."*

Some acknowledged the need for consideration of older people's specific issues, but saw this as part of their overall strategic plan:

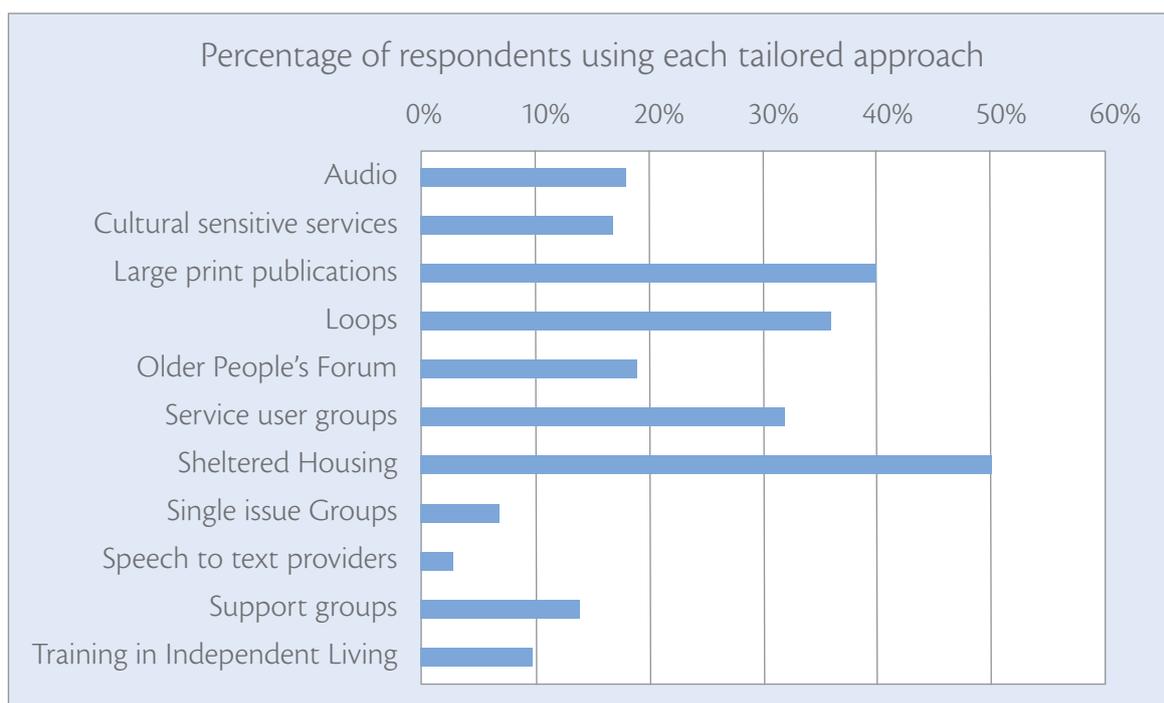
- *"We intend to embed the needs of older people into a generic approach to supporting all vulnerable tenants. Will develop skill strands such as dementia awareness/responses but not keep them as 'specialist' strands."*
- *"Whilst there are no concrete plans in place, we are constantly developing strategies."*
- *"As part of continuing development of our Asset Management Strategy in terms of our older persons accommodation and as part of delivering our Older Persons Strategy."*
- *"A strategic plan to be developed 2013/14 to respond to changing needs of older residents."*

## Section 3: Engaging with older people

Do you have any 'tailored approaches' for delivering services to older residents? Please tick all that apply.

The majority of respondents used one or more tailored approaches for delivering services to older people. The most frequently used approaches were Sheltered Housing (50%), Large-print Publications (40%) and Loops (36%). Service user groups were used by nearly one in three organisations (32%).

The least common approaches were Training in Independent Living (10%), Single issue groups (7%) and Speech to text providers (just 3%).



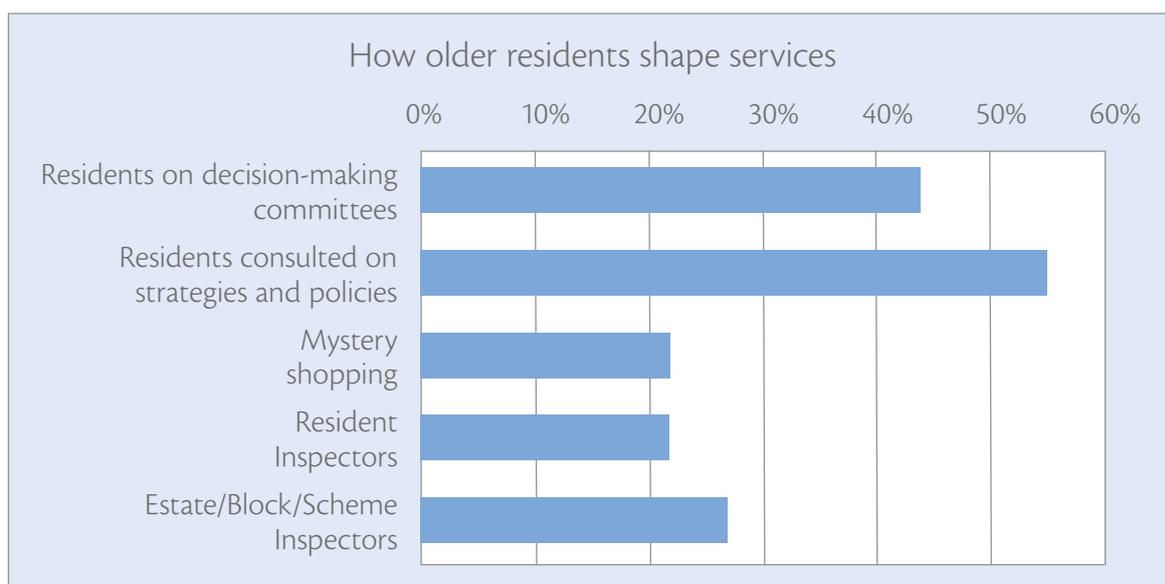
	Numbers Responding	% of overall respondents
Audio	16	18%
Cultural sensitive services	15	17%
Large print publications	35	40%
Loops	32	36%
Older People's Forum	17	19%
Service user groups	28	32%
Sheltered Housing	44	50%
Single issue groups	6	7%
Speech to text providers	3	3%
Support groups	12	14%
Training in Independent Living	9	10%

Nine respondents cited other tailored approaches they employ for delivering services to older residents. These included:

- *“Our parent organisation Racing Welfare has local welfare officers in each of the key Horseracing centres and they provide a person centred approach to delivering advice and support. They work closely with other external agencies in delivering the individual support required to enable our tenants/beneficiaries to live independently for as long as possible.”*
- *“Designated accommodation supported by community alarm and telecare.”*
- *“Planning upgrade to web site accessible to older people.”*
- *“Care homes, Extra Care schemes and Domiciliary Care.”*
- *“Floating support service.”*
- *“Tenant Boards to look at any issues and how to help run the association but all for people with learning disabilities.”*
- *“Health prevention service, developing self-directed care service.”*
- *“Housing with Care.”*
- *“Coffee mornings/ vulnerable persons monitor.”*

### How are your older residents able to shape the services you deliver?

Respondents were asked to indicate all methods that apply, and the majority used more than one of the named ways to enable older residents to shape the services that they deliver. The most common method cited was ‘Residents consulted on decisions and strategies’, noted by over half of all respondents (53%), followed by engaging residents on decision-making committees (44%). Use of mystery shoppers and resident inspectors were the least popular of the listed methods; although just over one in five of all organisations responding used both of these (both 22%).



	Numbers responding	% of overall response
Residents on decision-making committees	39	44%
Residents consulted on strategies and policies	48	55%
Mystery shopping	19	22%
Resident Inspectors	19	22%
Estate/ Block/ Scheme Inspectors	24	27%

Thirteen organisations commented or cited other methods by which residents can shape the services they deliver. Most include older people in the decision making and review procedures on a regular basis. Some ensure that older people are represented on the management committees/ trustee boards of their organisations. Most cited more than one way older tenants can get involved, giving a choice which promotes inclusion.

These included:

- *“As a small specialist housing provider we have regular face to face contact with our tenants and hold formal consultation meetings on a quarterly basis. We provide a responsive service that meets with the changing needs of our tenants.”*
- *“We also have a tenant scrutiny panel that operates independently of the tenants’ panel.”*
- *“Two tenants on the board. Small association with all tenants having easy access to all staff and board members.”*
- *“Residents on recruitment and scrutiny panels”*
- *“Board members, Service scrutiny panels, formal complaints learning.”*
- *“Targeted consultations.”*
- *“Two Resident Board members and a separate resident scrutiny panel.”*
- *“Older people are involved in our involvement and scrutiny structures including our review committee which this year is working with officers to carry out a review of the Heantun Group’s approach to nutrition and older people, a topic chosen by residents and to cover both Heantun’s housing and Heantun Care’s nursing home activities.”*
- *“All ages of tenants are represented in our various Resident Involvement strands and older tenants are well represented on our Board and other resident groups.”*
- *“Rooftop provide lots of different ways to communicate with all of its residents”.*
- *“Residents’ panel which is mainly over 60s.”*

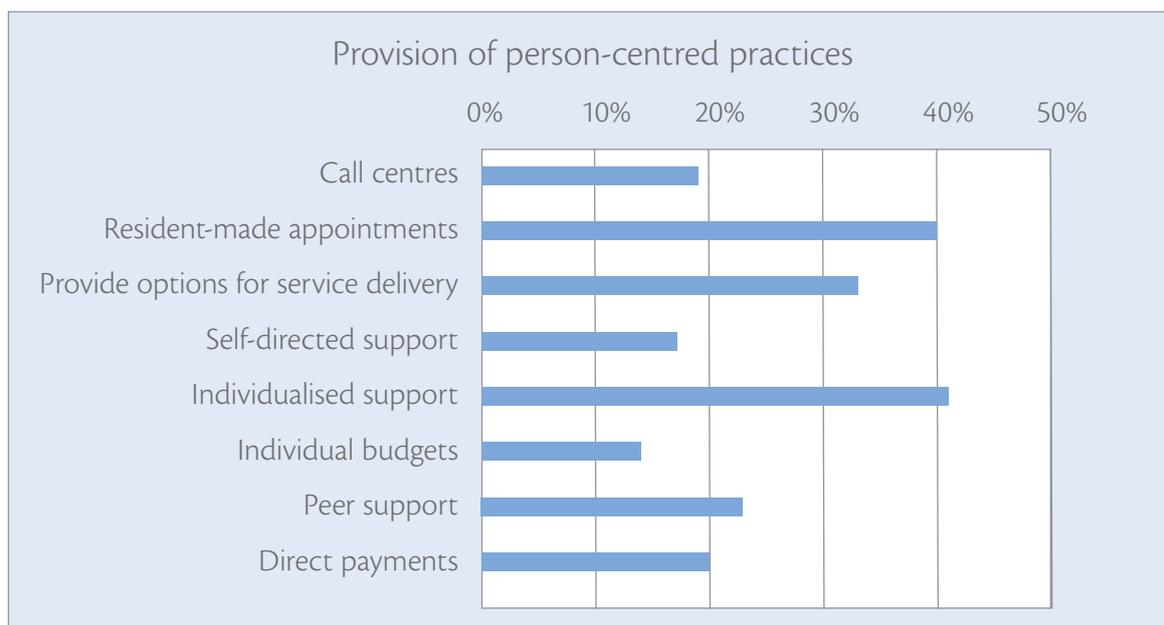
Two organisations stated that where one traditional way of engaging older people (such as a tenants’ committee or residents’ association) has failed, they have adapted their approach, one by carrying out customer surveys to ensure residents’ views are captured; the other, by providing different, more popular ways to engage:

- *“We have offered to set up a tenants committee but they are not interested and surveys have shown they are more than happy with things the way they are. We are only small, twenty three properties in total.”*
- *“The Residents Association folded due to lack of support and was replaced by a quarterly meeting attended by senior staff and a member of our Board of Trustees. Residents consulted where possible in many different ways. Residents invited to have input at interview for support staff and gardening staff”.*

## Do you provide any of the following person-centred practices? Please tick all that apply.

The most commonly cited person-centred practice was individualised support, cited by just over four in ten organisations (41%). This was also echoed in several other comments throughout the survey, that as small organisations, the approach is often tailored to the individual.

Resident-made appointments were almost equally as popular (40%). Least popular methods were self-directed support (17%) and individual budgets (14%).



	Numbers responding	% of overall response
Call Centres	17	19%
Resident-made appointments	35	40%
Provide options for service delivery	29	33%
Self-directed support	15	17%
Individualised support	36	41%
Individual budgets	12	14%
Peer support	20	23%
Direct payments	18	20%

Only four people made comments or cited other methods. These included:

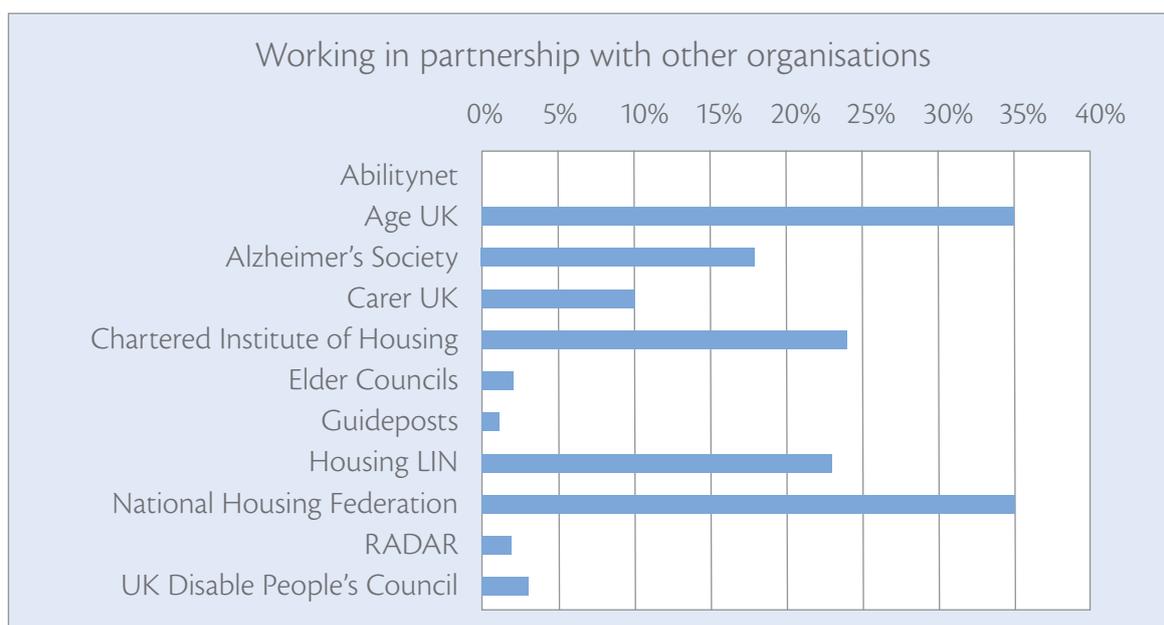
- *"Support plans are tailored to the individual needs of our tenants in our sheltered accommodation"*
- *"Are call centres person-centred?"*
- *"Most tenants have external support agencies to help deliver these support strategies."*
- *"Very small organisation, we deal individually."*

## Section 4: Partnership working and looking ahead

Do you work in partnership with any of the following agencies or organisations to inform service delivery to older residents? Please tick all that apply.

Age UK and the National Housing Federation were most commonly cited as organisations or agencies with which respondents work to inform service delivery to older residents: 35% of respondents engage with these organisations. The Chartered Institute of Housing was third most common, with nearly one in four organisations partnering with them (24%).

Low numbers of respondents reported working with Guideposts (just one organisation); Elder Councils (two organisations) and RADAR (two organisations). Nobody cited Abilitynet as a partner.



	Numbers responding	% of overall response
Abilitynet	0	0
Age UK	30	35%
Alzheimer's Society	16	18%
Carer UK	9	10%
Chartered Institute of Housing	21	24%
Elder Councils	2	2%
Guideposts	1	1%
Housing LIN	20	23%
National Housing Federation	30	35%
RADAR	2	2%
UK Disabled People's Council	3	3%

One organisation said that it was in the process of developing links with Age UK and seven others also mentioned other groups or agencies that they work with:

- Housingnet
- Chichester Careline
- EAC (the Elderly Accommodation Council)
- Local groups - M3A etc
- National Dementia Alliance, Worcester University Dementia Faculty
- Local district led forums
- EROSH (The Essential Role of Social Housing)

Other comments included:

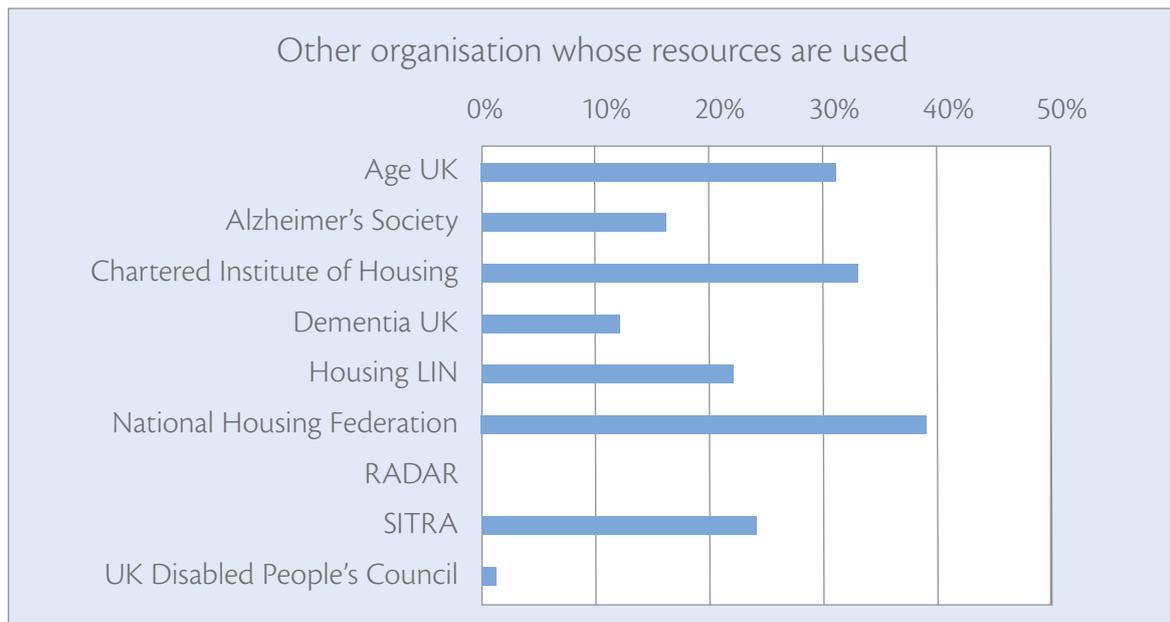
- These are not specific partnerships
- I don't know as I work in property services

### Do you draw on resources from any of the following organisations in your day-to-day work?

Respondents were asked to name any of these organisations whose resources they use in their day-to-day work. As with the previous question, Age UK, the National Housing Federation and the Chartered Institute of Housing were the three most commonly cited organisations, although in this case, the National Housing Federation was the most popular (39% of respondents), followed by the Chartered Institute of Housing (33%) and Age UK (31%).

SITRA was cited by nearly a quarter of all organisations (24%), and Housing LINs were also mentioned by just over two in ten organisations (22%).

No organisation stated that they draw on resources from RADAR, and only one organisation referenced working with the UK Disabled People's Council.



	Numbers responding	% of overall response
Age UK	27	31%
Alzheimer's Society	14	16%
Chartered Institute of Housing	29	33%
Dementia UK	10	12%
Housing LIN	19	22%
National Housing Federation	34	39%
RADAR	0	0%
SITRA	21	24%
UK Disabled People's Council	1	1%

Only two respondents mentioned other organisations whose resources they draw on:

- Northern Housing Consortium, Telecare Services Association (TSA).
- Learning Disability Charities such as Mencap, Autism Awareness etc

### Are you aware of the Orbit Charitable Trust resource pack?

There appears to be low awareness of the Orbit Charitable Trust's resource pack at present. When asked if respondents were aware of the Orbit Charitable Trust resource pack:

Nine out of 88 respondents said yes, they were aware of it. However, although numbers were very small, it appears more likely that smaller organisations are aware of it than larger ones. Of these nine responding positively to the question, six had a stock size of less than 1,000 and the remaining three had more than 1,000 properties.

Forty-seven out of 88 respondents said that they were not aware of the resource pack. Of these, 21 had a stock size of less than 1,000, while the remaining 26 had more than 1,000 properties.

32 individuals did not respond. Of these, 13 had a stock size of less than 1,000; 10 had a stock size of more than 1,000 and nine had not provided data on stock size.

This would seem to provide significant opportunities for raising awareness of the pack.

### This survey will inform our research going forward. Would you be interested in attending an event on people-centred services and/or taking part as a case study?<sup>2</sup>

There appears to be a strong interest in Orbit's future research work from those responding to this survey. Of all respondents, thirty five organisations (40%) would be interested in attending an event on people-centred services. Of these, 16 have stock-sizes of less than 1,000; while 19 have stock-sizes of above 1,000.

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<sup>2</sup> A list of these organisations with contact details will be supplied separately.

Nine organisations would be interested in being a case study (eight of whom would also attend an event; four of which have a stock-size of less than 1,000; five of whom have a stock-size of over 1,000).

Nineteen organisations would not be interested in either attending an event or being a case study; and twenty-five organisations did not respond to this question.



## Annex A – Methodology

The final response to this survey, carried out over a period in June and July 2013, was 88 out of 294 mailed, which equates to a response rate of around 30%. This is considered relatively high for surveys of this nature.

Steps taken to ensure a good response rate were as follows:

- A pilot survey with ten organisations was run prior to full roll-out. Eight of these organisations responded. Only one organisation made detailed comments on the nature of the questionnaire.
- The full survey was sent via SurveyMonkey on 17 June 2013. Of the 294 people mailed, 45 responded by completing it. Where respondents replied that they were no longer with the organisation, or no longer in a role where they felt they could answer the questions, the survey was redirected if possible to another appropriate individual.
- Analysis of early responses showed that some respondents had trouble answering the question relating to a breakdown of the age categories of their client base and ensuring this totalled 100%. Although the question was not mandatory, and was tested rigorously internally, it was felt that it was proving a deterrent to gaining full completion.
- For the reminder process, therefore, the position of the question was altered so that it appeared towards the end of the survey; and the requirement to make percentages total 100% was removed (although it was still stated that this was desirable). Interestingly, none of the respondents to the reminder cited trouble in completing this question and the response rate to it was far higher (56% compared with 29% of the first mailing). The substance of all questions for the reminder remained exactly the same, so that the results from both are comparable. The reminder was issued on 10 July 2013 and generated a further 35 responses.
- The eight completed forms from the pilot have also been included in the analysis of the overall responses, as they had fully completed the survey with accurate answers.





## What people said about the survey results

Researcher **Moyra Riseborough**, one of the country's leading social housing experts and the author of OCT's original research report

*"No one can afford to ignore the findings of the report. Social housing tenant populations are ageing so no one can afford to ignore the implications of ageing on their services and arrangements."*

*"We have to invest more in different approaches; one is to develop older people's capacity to help themselves and the communities they live, and the other is for staff and Board Members to adjust to the challenges of having an ageing population and learn to work in ways that best support older people."*

**Jeremy Porteus**, director of Housing Learning and Improvement Network and chair of Homes and Communities Agency's Vulnerable and Older People's Advisory Group

*"The survey highlighted that the overall level of awareness of dementia needed to be improved among housing providers."*

*"There need to be ways of both assisting tenants and residents and their carers and a greater appreciation of the different types of dementia so that they can get the support they need for everyday living."*

*"For smaller providers, particularly for their housing managers and staff, they are able to draw on training workforce development and peer mentoring, working with dementia specialists."*

*"I've spent 25 years working in housing for older people so I wasn't surprised with the headline findings, although I was more surprised to find that not more has been put in place."*

*"Over the past year we have been greatly helped to a high level by the Prime Minister's Dementia Challenge because it has captured people's imaginations."*

*"The key now is to use the survey findings in a pro-active way to help housing organisations build a strategy to adapt and develop ways of supporting people with dementia."*

**Paul Tennant** Orbit Group chief executive and president of the Chartered Institute of Housing.

*"We have known for some time that the demand for older people's housing and care will only grow as our population ages, which makes the results of this survey surprising in the lack of preparedness they seem to highlight."*

*"It is vital housing associations can deliver appropriate services to those with dementia, whether working in partnership or delivering those services in house, and a dementia strategy provides the robustness needed to do that."*

*"I would urge the sector to take this research to heart and think through how they are going to help current and future sufferers, their family and those working with them, to live as well as possible with dementia."*



# Becoming a dementia friendly organisation

## Small Housing Associations Show the Way

***“Dementia is a ticking time bomb and we have to do everything we can to make sure that housing providers have adequate provision in place to provide for the needs of people who are living with the condition,”***

**David Hucker, Chairman, Orbit Charitable Trust**

At a learning day in September sponsored by Orbit Charitable Housing Trust, a group of small housing associations took time out to share their good practice on services for people with dementia and their carers. They also laid radical plans for the future and we can all learn from their commitment to carry on sharing their learning during 2013 and 2014.

### Learning Day Aims – for small housing associations to:

- Share good practice and learn from each other
- Using prepared scenarios consider how to work in dementia friendly ways
- Develop an action plan
- Consider working towards being an accredited dementia friendly organization.

In this short report we share the highlights with you. There will be more to come over the next six to twelve months.

### Who took part?

The small housing associations are Racing Homes, Endeavour Housing Association, Innisfree Housing Association, Women’s Pioneer Housing, Industrial Dwellings Society, Heantun Housing Association, Waltham Forest Housing Association and Sutton Housing.

Also in attendance were David Hucker, Chair of Orbit Charitable Trust, Jeremy Porteus Director of the Housing Learning and Improvement Network and Esther Watts from the National Alzheimer’s Society. The event was facilitated by Moyra Riseborough and Adrian Jones from RRCA<sup>2</sup>.

### Why dementia is so important

Dementia is the biggest challenge facing society. About 670,000 people currently live with dementia and around two-thirds of them are cared for in the community. The number of people with dementia could double within 30 years. Government estimates that dementia already costs society £19 billion a year – more than cancer, heart disease or stroke. The Prime Minister, David Cameron, last year described the rise in dementia cases as a “quiet crisis” when he launched the Dementia Challenge. He called for the UK to become a world leader in dementia research, the creation of dementia-friendly communities, and greater awareness and understanding by healthcare professionals.

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<sup>2</sup> Riseborough Research and Consultancy Associates.

## From dementia friendly communities to dementia friendly housing organisations

This year the Alzheimer's Society and the National Dementia Action Alliance launched a campaign to encourage dementia friendly communities. The learning day went further and asked small housing associations already interested and working on developing good dementia practice to share their learning and consider becoming dementia friendly organisations.

There are no blueprints to produce the definitive dementia friendly organization but Moyra and Adrian from RRCA drew on the available evidence to produce several helpful resources including check lists. The checklists help organisations measure how dementia friendly they are right now. For more information on the resources developed for the day see the Orbit Housing Charitable Trust website.

### **Jeremy Porteus** – Director Housing Learning and Improvement Network

Keynote speaker Jeremy Porteus noted that attention to the issue of dementia has increased in the last 3-5 years. He talked about the urgent need for good research.

*"Good quality research on the topic is essential to build the evidence base to inform innovative policy and best practice and he thinks that it is lacking for commissioners, providers and carers; and the lack of good research makes it harder to put a case for change and influence the allocation of necessary capital and revenue funding to meet the housing and care needs of people with dementia."*

Although we need more research some things are already well known. The evidence shows, most importantly, that

*"If we get the care, accommodation and environment right to support people then those living with dementia can live up to 15 years longer. There is thus a clear need for dementia-led approaches."*

Jeremy commended Orbit Charitable Trust and the researchers for putting dementia on the radar for small housing associations.

### **David Hucker** – Chairman, Orbit Charitable Trust – gave the Trust's rationale for commissioning the latest work from RRCA

*"Dementia is one of the greatest problems landlords are going to have to face" and there was therefore an urgent need to share and develop good practice particularly amongst smaller housing associations.*

Referring to initial survey work carried out by the Trust he noted that of the 88 respondents to a survey by the Trust asking small housing associations about their approach to dementia, only 8% (7) said they have a dementia strategy in place. 63% (55) said they did not have a dementia strategy drawn up.

Of those, 24% (13) said they did not need one; the same number said a strategy was being developed, while 12 said they had not yet thought about it. Most housing groups who responded to the survey said a separate dementia strategy was not necessary because of the size of their organization.

### **Esther Watts**, Dementia Action Alliance Coordinator (the Alzheimer's Society

Esther talked about the dementia friendly community's campaign and her work as the Dementia Action Alliance Coordinator for London and the South East) and in particular about the Dementia Action Alliance (DAAs).

The National Dementia Declaration (developed by people with dementia and their families with support from major charities such as the Alzheimer's Society and Age UK and professional bodies such as ADASS and the Royal Colleges) was introduced in 2010. To join the DAA an organisation has to sign up to the values of the declaration and identify three things that the organisation could do.

Over 220 organisations have signed up to the Declaration so far, including:

- Major charities – Alzheimer’s Society, Age UK, WRVS
- Department of Health
- All relevant Royal Colleges
- Care providers: Bupa, Four Seasons, Barchester
- Growing number of commercial organisations
- Local Authorities

Declaration Signatories submit an Action Plan. Esther said it’s an *“I will if you will philosophy – not just asking others but actually doing”*. Action Plan commitments vary from Bupa training 204 dementia champions, Age UK who are trialling dementia strategy in 9 care homes, British Psychological Society who are developing guidelines on alternatives to antipsychotics, the Design Council who is running a £350,000 design competition.

Esther suggested that dementia-friendly communities are where we want to be in terms of a long term goal for society. Local DAAs (of which there are now 44) are a vehicle by which to get there.

DAAS can include the following members, Retailers; Bus companies; Taxi firms; Community groups; Faith bodies; Local authorities (e.g. Trading Standards and Parks and Recreation); Health Trusts; Commissioners; Housing providers; Emergency services and Arts/leisure organisations. It isn’t just social care and health by any means.

***“A bonus if you are looking to develop links with commissioners”***

The DAAS could provide the very links that small housing associations at the workshop were looking for – particularly now when everyone is trying to remake or strengthen links with health and social care commissioners.

Local DAAs Members need their organisations to agree to carry out Actions to become more dementia friendly. Local DAAs range from the village, to town, city and regional Dementia Action Alliances. All are sharing good practice and projects to spread knowledge about how to improve communities for people with dementia and their families.

Although Alzheimer’s Society takes the Secretariat role (with funding from the Department of Health), the Society is an equal member on any Alliance. There are regional officers who will help set up an Alliance. The following resources are also available:

- Tool kit for establishing Local Dementia Action Alliances
- Guidance notes and action plans for different organisations: commissioners, councils, businesses, voluntary and community groups, etc.
- Members featured individually on Dementia Action Alliance website
- Access to Dementia Champions training
- External evaluation by ICF CHK

*“Small Changes, Big Differences”* gives useful real ideas from communities who are acting to help create dementia friendly communities, (see Appendix 1).

# What are small housing associations doing already?

## Preparations

Before the learning event participants read a briefing paper and they prepared a description of what they currently do to assist people with dementia and their families. They were also asked to say where their organisations want to get to in terms of being dementia friendly organisations.

## Endeavour

- Routinely carries out health and safety checks
- Uses dementia friendly colour coding in its new build Extra Care (although it is recognised that more could be done with older buildings)
- They do a lot of multi-agency work
- Recently had an inter-generational project on World War 2 which engaged people with dementia along with other Elders
- A review of older people's services is underway that is looking at all options

Endeavour did not have a dementia strategy but all staff in its Older Person's Department receive dementia awareness training. However, since a large proportion of older people living in general need accommodation it is recognised that this training needs to be rolled out to the wider organisation. Endeavour staff at the learning event said that they also noted training needs to become a rolling programme rather than a "one off".

Staff said that tenants with dementia could benefit from something quite low key such as someone visiting them a couple of times a week – the opportunity to have a chat can be the most important part of the support.

## Industrial Dwellings Society

- Have an agreed Emergency Contingency Plan with the Police to ensure that if a resident is found wandering – police know residents have a piece of paper with a phone number to IDS on them.
- Regular health and safety inspections of flats are carried out
- Inter-generational work (e.g. at Xmas and Harvest Festival) is carried out
- Scheme Managers get regular training on dementia awareness from Alzheimer's Society, although office-based staff could also benefit from this.

A suggested improvement was that a bookmark or business card could be produced and circulated on the back of which would be 5 key points about dementia.

## Heantun Housing Association

Heantun Housing Association has some 1,200 properties (mainly new build) on which half are supported housing. The association has some 350 properties (including traditional sheltered accommodation and bungalows) in the Black Country for older people. 10% of tenants have a learning disability.

The association provides housing, care and support - the organisation's care arm (Heantun Care) manages

nursing homes (including some offering specialist dementia care) and runs community services.

Wolverhampton has declared itself a dementia friendly city. In Partnership with a local university HHA has implemented a training programme on dementia for almost all staff at all levels (from Board member to gardener). Staff at the learning event said the consequently staff at all levels understand the key issues and are “dementia aware”.

A big “plus” is that staff are now more confident in managing situations where a tenant has dementia and is also more confident in supporting the families of those with dementia. The process took at least a year and is on-going.

Since it is a small organisation it seems that communication across sub-organisations is better than in many larger organisations. Heantun also has a good relationship with dementia advisors at the local hospital. This led to Heantun setting up an informal pilot to look at the support people need to stay in their own homes.

Further issues that were identified as areas for improvement were:

- The need for benchmarking re. Dementia training.

The need for awareness training for dementia sufferers, their families and those living around them (for example, there can be prejudice in sheltered accommodation among other residents against those with dementia).

### **Innisfree Housing Association**

Innisfree is an Irish-facing, mostly North London-based organisation with some 550 properties. In recent years its focus has been on supported housing (it has one sheltered scheme and 100 homes supported outside) although it is not a direct support provider. The Association is aware there are many older people living in its general needs accommodation.

Innisfree is acutely aware of the culturally-specific aspects of dementia. They include for staff and family members, remembering the location where people’s recollections are strongest. This is often an Irish location both in terms of place and people. Also being familiar with a preferred form of address which often involves a degree of courtesy and respect for people.

Cultural specific points of reference also include staff and carers having an understanding of the politics of Ireland and England because they are so central to people’s beliefs and identity. These factors are so important for many people who migrated to England and elsewhere.

Actions taken by the Association include:

- 2 sessions on awareness raising on dementia for staff
- Action to develop a memory-loss friendly environment
- A Heritage Lottery Fund project for reminiscing (including both sheltered and non-sheltered tenants) – this was viewed very positively.

### **Racing Homes**

The organisation’s mission is to enable tenants to stay in their homes as long as possible, They:

- Try to promote early diagnosis
- Work with tenants on accessing support
- Work with families

- Have invited Alzheimer’s Society to talk to tenants and staff
- Are good at working in partnership

The organisation’s welfare team has a staff training plan on dementia (some staff have completed this; others are yet to do it). They have a dementia specialist in their team who is a “Champion for dementia”.

Staff from Racing Homes said the Association recognises the need to improve the way they share resources and work with partners. Different parts of Racing Homes could also work better together.

The organisation’s wish list includes the following:

- It needs to adopt the personalisation agenda
- It needs to improve technology, memory aides and signage
- It needs to develop a floating support and befriending scheme
- The welfare team could develop Tenant Personal Profiles, so that they know all about their tenants
- The organisation could build on the shared memories (horse racing) of its tenants

### **Sutton Housing Society**

With some 400 properties SHS’s core business is sheltered accommodation (11 schemes).

The Society:

- Do support planning
- Carry out fire risk assessments – as a result they will have no more gas cookers
- Are up-grading their alarm call systems
- Have colour-coded floors in their schemes to assist those with dementia
- Have moved away from the use of agency staff to cover for leave/illness, so that tenants can be more familiar with cover staff.
- Have obtained Department of Health money to improve the living environment for those with dementia – one of two successful bids from housing providers.
- Has “dementia awareness” champions among their Scheme Managers and there are plans (after training) to introduce “mental health in older people” champions.

Issues raised by the staff included the following:

- Following their training Scheme Managers are able to act as “trusted assessors”. Local Social Services officers are, however, loathe to engage with them.
- The Society doesn’t have a dementia strategy, although they want to adopt one so long as it is realistic and possible to implement.

### **Waltham Forest Housing Association**

Described itself as a “small provider with a big voice” WFHA looked at what the organisation did on a day-to-day basis. They avoid stigmatising people with dementia, monitor changing behaviour and changing need (which is helped by Support Plans) and give advice and guidance regarding daily living.

Actions WFHA have taken include:

- Reminiscence work with customers and staff
- Intergenerational work with schools e.g. around shared experiences such as the seaside then and now – interaction between young and old is seen as invaluable
- Raising safeguarding alerts, although it is recognised that this requires partnership work (housing can't do this alone!) including all key agencies (Police, Adult Social Care, Safe Neighbourhood Team, Fire Service, Environmental Health, District Nurses, families and carers etc.)
- Using the Common Room in a sheltered scheme for a Dementia Support Group

### **Women's Pioneer Housing**

WPH house single women, mostly in Kensington and Chelsea. They have been developing a floating support service over the past two years, with sheltered scheme staff going into properties in the association's more general stock (where people can be much more isolated).

A number of pressures were identified:

- Tenants with dementia may not see that they have a problem
- Staff and relatives may expect WPH to do more than is possible or appropriate. For example, when tenants who could be regarded as making unwise choices still have the right to make those choices.
- Since staff work for their landlord tenants may view them as an enemy not as a friend
- Head Office staff may view frontline staff as an irritant

Live-in staff and estate officers are now carrying out small repairs in several buildings. As a result they can often identify issues that may otherwise go unidentified e.g. hoarding, smells, and poor state of repair.

## Are you dementia friendly?

Each of the associations compared their practices, policies and procedures to a check list produced for the learning event to enable organisations roughly assess their dementia friendliness (Appendix 2).

All participants agreed that their organisations were not totally dementia friendly – yet!

### Learning points

#### **Active steps towards being dementia friendly included:**

- Having a learning day and deciding to carry on swapping practice and lessons between organisations (and inside different parts of organisations) is a great start
- Making a statement of intent (“we want to be dementia friendly”) and communicating it to your staff, tenants and relevant agencies
- Keeping things fresh/active
- Use the check-lists so you can see where you are

- A dementia friendly organisation recruits dementia friendly staff
- We need to think about how we respond to our staff who may develop or are supporting relatives and loved one's with dementia
- We need to engage better with our tenant and residents families and friends when people have dementia
- Person-centred ways of working should be adopted and tenants should be engaged in shaping services.
- Tenants should be visited regularly (every 6 months)
- Intergenerational work can have real benefits
- There is a role for befrienders
- Staff need to understand the cultures and histories of their tenants
- A dementia centre could be created
- Physical improvements (such as colour coding, telecare, design features) should be made to sheltered schemes, but we need to think about people ordinary housing too.
- "Dementia" is a loaded term that needs to be confronted head on – to do this staff need to have the necessary confidence and make it our normal work
- A "whole organisation" approach to training is needed – for everyone
- Training – it's one of the strategies that should be adopted, not the only strategy
- An organisation needs a "dementia champion" – someone with passion who can network and co-ordinate everything that is going on – but makes sure everyone continues to learn across the organisation.

### **Next steps and useful links**

The small organisations who took part in the learning event are committed to continue to talk about becoming dementia friendly and to sharing their learning and practice in 2014.

To see the small housing associations action plans and all the resources developed for the learning day plus forthcoming outputs on Towards Becoming Dementia Friendly see the Orbit Charitable Trust website

[http://orbit-research.org.uk/?page\\_id=20](http://orbit-research.org.uk/?page_id=20)

To find out more about RRCA see [www.rrca.co.uk](http://www.rrca.co.uk)

*Becoming a dementia friendly organisation: Small housing associations sharing good practice and learning together" was organised for the Trust facilitated by RRCA and held on 30th September 2013 at the National Housing Federation in London*

# Appendix 1

Local Dementia Action Alliances



## Small Changes, Big Differences.

The following gives a list of ideas that many communities are putting into action to help create dementia friendly communities.

- Raise awareness and understanding of dementia amongst the whole community
- A dedicated 'no hurry' checkout lane in supermarkets.
- Individual arrangements with local shops, services etc. between owners and people with dementia/families/carers to support them to continue to enjoy daily/weekly/monthly activities, eg arranging for family/carer to pay for hairdressers, newspaper at end of the week.
- Having a nominated dementia champion within a company that can be the point of contact for staff (and costumers) on issues associated with dementia.
- Informing retailers about the use of chip and signature cards.
- Tours of theatres, galleries, public buildings etc. by people with dementia to offer suggestions for better customer care or environmental factors (signage, lighting, space). For example in the theatre having dedicated seating set aside that is near to exits or aisles so people can leave if necessary.
- Local branches of banks to go and give talks to local memory cafes about financial issues and what support the bank can offer, eg chip and signature cards.
- Local police to visit memory cafes to talk about community safety and support.
- Pharmacies to visit memory cafes to talk about what they offer as well as having a list of local support groups and information of where to get help on a notice board or in a folder
- Opticians & Dentists - awareness training and support
- Producing a very quick reference guide for local shops/businesses with details of where they can get help or advice if they meet someone who has dementia that needs support (eg local numbers for GP/Carers Organisations) in their community.
- People with dementia (memory cafes) doing a 'walking tour' of town centres and offering suggestions about environmental issues, signage, accessibility.
- Schools including dementia throughout the curriculum and having opportunities to educate through creative arts, linking with local residential/nursing homes
- Local Parks/Leisure facilities - look at facilities, safety, walking routes.
- Working with local Chamber of Commerce or Business Improvement Districts (BIDS) to promote work of local alliances and raise awareness to its members.
- Providing a sticker/logo to businesses/retailers to show that they are dementia aware.

For more information on any aspects of this document please contact Carol Clifford, Project Manager, West Region Alliances on 07715 805662 or email [carol.clifford@alzheimers.org.uk](mailto:carol.clifford@alzheimers.org.uk)

## Appendix 2

### Check List – towards a dementia friendly housing organisation

Practice		Tick if yes
All members of staff	Are aware of different types of dementia	
	Demonstrate respect for people with dementia	
	Communicate well with people who have dementia	
	Know to ask people why they are worried/upset and will listen/observe	
	Know to ask people why they are worried/upset and will listen/observe	
	Know why some people 'wander' e.g. anxiety, looking for the past, boredom	
	Understand the importance of activity /exercise for people with dementia – i.e. 'safe' exercise/activity	
	Have some experience of person centred working	
	Know about strategies for managing risk – expect people to take risks	
	Expect people to be able to live independently for considerable time	
	Feel confident talking about dementia with other people/residents	
	Feel it is right to support someone with dementia	
	Enable and support lots of interesting activities to engage residents	
	Expect others to support individuals and carers as well	
	Want to get rid of the stigma attached to dementia	

Design	Our specialist buildings/care homes don't have long institutional corridors	
	No mirrors in areas where people walk about	
	No mirrors in areas where people walk about	
	As much natural light as possible	
	Brighter than average artificial lighting	
	As many opportunities as possible for people to see outside	
	Colour and tones are used to mark difference between walls and the floor	
	Artwork and other features to mark changes in direction	
	Clear signage but not too many signs	
	A monotonous line of doors is avoided	
	Acoustics are thought out so noisy rooms are separated from sleeping / living areas	
	Assistive technology supports people to manage risks it does not offer surveillance	
	Circuits are provided for safe walking inside and outside together with seats	
	Outside space has areas and features of interest e.g. sculptures/seats	
Policies	We have a policy to support members of staff who develop dementia	
	We have a policy to support staff whose relatives develop dementia	
	We have a dementia strategy	



# Developing A Dementia Strategy – A Quick Guide

## Objectives

Housing associations need to recognise, plan, develop and tailor outcome-based personalised services for residents by having in place a strategy that :

- Is coherent
- Represents a consensus within the Management team or team of Trustees
- Has been communicated broadly
- Is financially viable
- Has agreed priorities
- Has a measurable implementation period
- Is built around and meets government and funders needs/guidelines
- Has a named person as lead
- Enables the person to 'Live Well'

## Outcomes

A model dementia strategy is one for which:

- Everyone is signed up to and, therefore, knows where the organisation is going in respect of those customers with a possible or actual diagnosis of dementia.
- Priorities are agreed and set and fully resourced
- The change agenda and its timelines are agreed by all
- Performance indicators are set with regular monitoring by both customers/residents and the organisation
- Outcomes meet best practice and current Government thinking

## Developing a strategy – background

The Prime Minister's Dementia Challenge launched in March 2012 sets out plans to go further and faster in improving dementia care.

Work included:-

- Improving Diagnosis rates
- Improvement to Health and Care Services
- Creating Dementia Friendly Communities
- Improving research into Dementia

Housing associations play an especially important part in the everyday lives of people with dementia. So how can you improve the way they work with residents and, in doing so, create within your organisation or service a dementia friendly community enabling residents to have a Home for Life and to live in a stigma-free society?

## Developing a strategy – outcomes

With public awareness increasing, the spotlight is now on Dementia. There will be over a million people with dementia in the UK by 2021. Dementia already costs the economy more than stroke, cancer and heart disease combined.

In developing a local strategy, associations will need to:

- Set a clear direction for their organisation
- Have an adopted direction of travel to ensure that current and future residents, some of whom may already have a diagnosis of dementia, remain at the heart of everything they do.

The result should be a strategy that includes:-

1. **A Foreword** from the Chair stating why the organisation is travelling this road. This will set the context for staff to engage and will demonstrate that this strategy is owned by the organisation.
2. **An executive summary** which will sum up your strategy for use by staff and residents. This is particularly useful if you plan a lengthy strategy document.
3. **An Introduction** containing statements on:
  - **Who you are**, your organisations size, location and philosophy etc.
  - **Where you, as an organisation are going**, i.e. your direction of travel, to include your commissioning intentions i.e. specialist housing, Extra Care, independent living.
  - **How** you will reach your goals.
  - **Your VISION and MISSION** in undertaking this strategy: you may want to do this through an event with Directors, staff and trustees.
  - **Your VALUES** showing that you as an organisation are:
    - **Inclusive**, namely you reach out to your community and respect and value their input
    - **Challenging**, you as an organisation welcome change and are constantly challenging yourselves in taking a lead in what you deliver
    - **aspire to excellence** in what you do
    - acting with **integrity** respecting and valuing people's views and treating customers with respect, dignity and fairness
    - **Enabling**, i.e. that you take staff and customers along with you on your journeys, helping people reach their full potential/make a meaningful contribution to their community.
    - **Inclusivity**, i.e. the organisations needs to build a strategy to adapt and develop ways of supporting dementia sufferers.
4. **Setting the Scene/Legislation**
  - Local and national policy and how it has or is being interpreted into local housing policy and more specifically how that will affect you and your residents
  - Clear reference to the Care and Support Bill which will become law in April 2014
  - Living Life to the Full, the National Dementia Strategy, Housing related strategies, Carers strategy refresh, Personalisation.

5. **Needs Analysis** National statistics and local statistics, these should be available from your local authority Observatory and will include actual and predictive figures. You may wish to include in this:

- Your own statistics on how many people you currently have with dementia, how many will develop the disease in the lifetime of your strategy
- Work you have carried out with staff and residents in respect of their needs/issues, this could include training needs
- Time lost currently to both call outs, incidents and to hospital admissions/GP visits in staff time
- Cost to the organisation in time and lost customers currently and in the future if your marketing does not make you a good provider and competitive in a growing market
- why you as an organisation are doing this, i.e. commissioning intentions, contracts with your local authority.

6. **Desired Outcomes** for both the organisation, its staff and the residents, this may include:

- Raising awareness and understanding through dementia awareness campaigns, information and advice, hosting dementia café type services
- Introduction or improvement through increased use of technology to support independent living, such as memory aides, medication reminders and GPS locators.
- Early diagnosis and training and support for staff/residents
- Creating or being part of a local dementia friendly community reducing stigma.

This could be a set of statements about how you will:

- Support timely and accurate diagnosis
- Post diagnostic support
- Working in partnership with key dementia organisations
- Linking into and being part of a dementia friendly community
- Housing related support and interventions
- In reach into communities
- Early intervention to prevent hospital admission or to promote early discharge home.

7. **Challenges for the organisation** including financial, board and staff training, responses of residents, working in partnership with Health and Social Care professionals, the community to deliver person centred support .

8. **Progress and Implementation** How to measure progress and achievements. This may include:

- Training for board members and staff to make them more aware and better prepared to deal with users
- Recruitment of dementia trained staff and personal development
- The need to recruit and retain local dementia champions from staff and residents.
- Working with GP's and broader health professionals to keep residents well and help them better self-manage their long term conditions.

9. **Appendices** These will include:

- Any research you have carried out to support the strategy
- Statistics you have but may not wish to add to the body of the strategy
- Training needs analysis for staff.

## Summary

The aim has been to provide a check list of the desirable features of a strategy, but your organisation must develop one that fits your individual circumstances and the end result will depend on:-

- how inclusive and readable you wish to make it,
- who your audience are and
- how the strategy will be used, namely as a marketing tool, training tool or as a change agent.

Lorna Ferguson

Wren Associates





# Laying the Foundations *for* Living Well with Dementia

*A Housing Support &  
Extra Care Housing Strategy*

*for Orbit Heart of England*

2012–2015

# Contents

1. Executive Summary
2. Introduction
3. Research, and Population Profile
4. More effective and responsive services
5. Conclusions and next steps
6. Appendix 1: Mapping of resources guide
7. Appendix 2: A Way Forward, Dementia Issues in OHE Sheltered Schemes
8. Appendix 3: Staff Training Audit tool

## Foreword:

Earlier this year, recognising the growing number of older people amongst its customers, many of who do not live in purpose-built accommodation, Orbit Heart of England (OHE) commissioned Orbit Charitable Trust to help look at its existing services and plan for the future, with particular emphasis on people with dementia.

The project involved a number of steps, namely:-

- An analysis of current profile of dementia issues and needs within each scheme, using hard and soft data sources, a map and an analysis of current community and statutory provision for dementia in each locality.
- A skills audit and training needs analysis of relevant team members, management and supervisory structures.
- Consultation with stakeholder groups to identify issues, perceptions, experiences, gaps in services and future concerns.
- Development of a training resource to enable workforce and individual development and awareness raising.
- The delivery of training and workforce development on dementia including supervisory structures, skills sharing and training needs recording.
- Exploration of assistive technology and future needs for current schemes not as an 'add on' service but a key part of everyday life.
- Exploration of tele-healthcare solutions to tenants including an examination of the infrastructure required for a successful tele-healthcare scheme and the need to measure the impact of tele-healthcare solutions. This will provide an evidence base of its benefits to enable further development of these kinds of services based on the cost saving impact for housing sector and on other arenas such as health and social care as well as the improved quality of life for the user.
- Produce a 3 year Dementia Strategy for SHOPs.

This document provides the framework for future working and a baseline for determining the training needs of those providing services to older people.

David Hucker  
Chairman  
Orbit Charitable Trust

# 1. Executive Summary:

This strategy sets out:

- Orbit Heart of England (OHE) strategic approach for community living within its older persons living and
- A new approach to their customers experiencing the onset of, and living with Dementia.

In undertaking this piece of work (OHE) have recognised that their current environment is not necessarily dementia aware and consultation has taken place with current (OHE) staff, residents, carers and key stakeholders.

## Purpose and clarity of this strategy

- This strategy highlights 'supportive living' as a combination of housing and much wider support that enables customers to live as independently as possible. This wider Dementia information and support given by (OHE) staff that will enable their customers to make informed choices about 'Living with Dementia' and having better control of their own lives in their local community.

## Understanding Dementia

- The term Dementia is used to describe a collection of symptoms including memory loss, problems with reasoning and communication skills. It is a reduction in a person's abilities and skills, in carrying out daily activities such as washing, cooking, dressing and caring for self.
- A correct medical diagnosis and a planned timely response to the customers' needs are essential if (OHE) are to successfully support the person through the 4 recognised stages. These 4 stages of Dementia are: 1: Early stage. 2: Middle stage. 3: Later stage. 4: End of Life
- (OHE) staff working with customers 'Living well with Dementia' need therefore to be aware of each Dementia stage, the responses needed to deal with them and the extent to which external agencies are able to support.

## The (OHE's) vision for customers '*Living Well with Dementia*' is that:

All (OHE) Older Persons Living Schemes will aim to promote the ethos of '*Living Well with Dementia*' to all their customers by:

- All staff having basic knowledge of those customers living with Dementia
- Key staff being dementia trained
- Promoting dementia awareness both within the schemes and the local communities.
- Developing wider partnerships in relationship to the dementia debate to enable staff to be confident in the support they give to customers.

## In delivering this vision (OHE) will ensure that all their customers:

- with or without a potential or actual diagnosis of Dementia will be given access to advice and information in a format enabling them to make informed choices about their care now or in the future.
- are supported to be as independent as possible
- are enabled to actively take part in their communities
- with Dementia requires Extra Care choices that are supportive, enabling for both the individual and where appropriate their carer/family.

## The Outcomes for implementing a Dementia Strategy:

The outcomes for (OHE) and its customers in implementing this strategy are;

### For (OHE) Management and staff:

- Well trained staff
- Well supported staff able to make more confident decisions when supporting customers
- Fewer complaints
- Informative, harmonious older persons living schemes

### For (OHE) customers:

- Improved health and emotional wellbeing
- Improved quality of life and personal dignity
- An understanding of dementia, and through this more tolerance towards others
- Less fear of the disease from a personal perspective
- Improved '*Living Well with Dementia*' support helping customers to make a positive contribution to their community, free from stigmatisation.
- Better information and communication channels leading to greater choice and control.
- Better informed and supported relatives and carers

## 2. Introduction:

### 2.1. The National Context:

The *'Living Well with Dementia'* National Dementia strategy 2010 (DoH)<sup>1</sup> provides a strategic framework within which local services can:

- Deliver quality improvements to dementia services and address health inequalities relating to dementia
- Provide advice, guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services and;
- Provide a guide to the content of high quality services.

The National Dementia Strategy sets out 17 objectives that the government wants the NHS, Local Authorities and others to take forward to improve dementia care services.

The recommendations are based on three key themes:

- Raising awareness and understanding
- Early diagnosis and support
- Living well with dementia

### 2.2. The Principles of Supported Living

Kinsella<sup>2</sup> set out five key principles of Supported Living:

- 1: Separating housing and support to provide flexible combinations of both.
- 2: Focussing on one person at a time, moving away from a group home model.  
This would involve using detailed person centred plans to provide services that are genuinely individualised
- 3: Zero Rejection meaning that nobody is seen as too disabled to live in their own home
- 4: Housing is centred on individual's own concerns, not those of organisations providing services which would give people much more control over their homes and lives
- 5: Making sure those relationships, family, friends and community are at the centre in the design of services.

These principles remain appropriate despite several changes in legislation over the last ten years and are crucial in defining supported living characteristics, the idea of separating housing and support plays a central role as this is a key factor to avoid the requirement to register a home. This has a number of significant effects on the whole system including increasing an individual's income, opening up different funding sources and promoting security of tenure.

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<sup>1</sup> National Dementia Strategy, Living Well with Dementia DoH 2010

<sup>2</sup> Kinsella 1993 cited in Social Care Research 1997

## 2.3. The Local Context

Successful collaborative working arrangements at both strategic and operational levels are vital in meeting the needs of people 'Living with Dementia'.

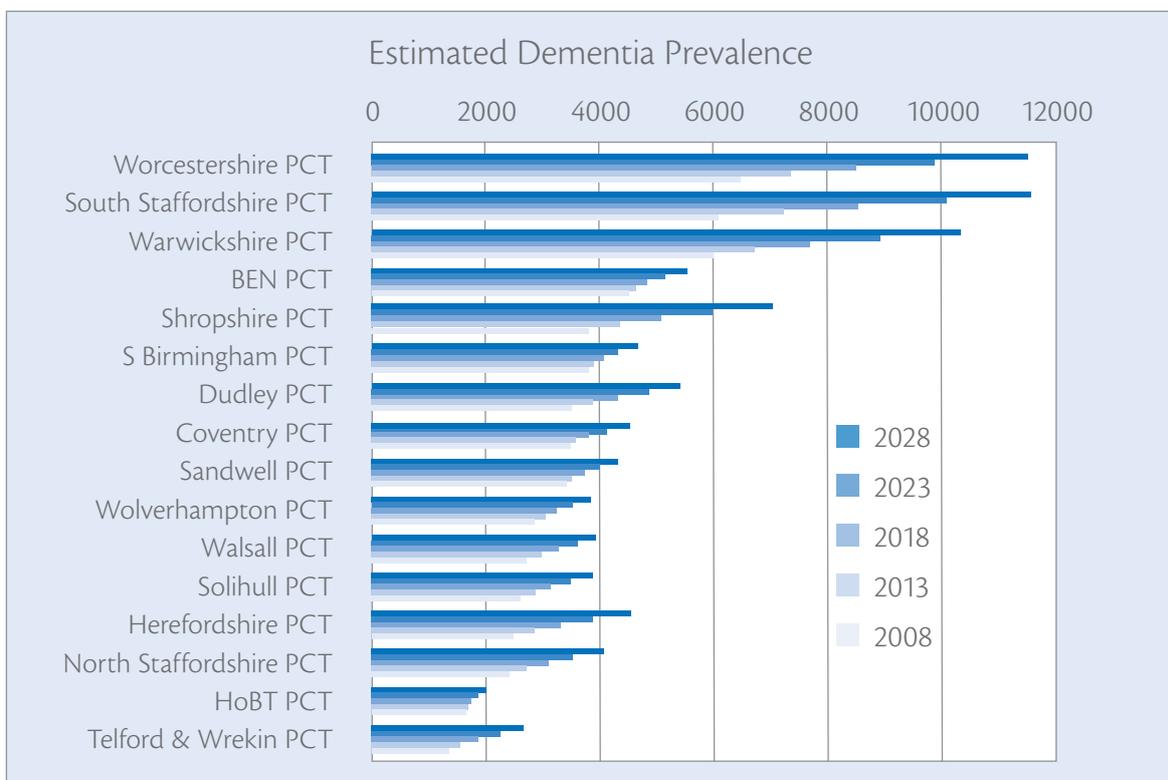
(OHE) recognise that collaborative working with partners is essential in delivering operational support to staff in their caring tasks and equally for operational and managerial staff in undertaking their roles locally.

Individual customers with dementia need to feel safe in the community in which they live. The health and safety within their home environment can be achieved with (OHE) staff being more dementia aware and better informed in their practice. Tolerance, understanding and the promotion of 'good neighbour-ship' from a customer base will in addition assist in enabling those customers with dementia to remain living in the community.

More particularly, collaborative working with statutory partners at the middle to later stages of dementia is essential and will include a review of the customer housing to ensure levels of support are appropriate and issues of risk are appropriately addressed.

### 3. Research and Population Profile:

- 3.1. Dementia is thought to be one of the biggest challenges facing the health and social care system in the 21st century.
- 3.2. Coupled to the increase in aging population the number of people with the condition will double over the next 40 years.
- 3.3 The West Midlands Observatory demographics indicate that the top three growth areas for dementia are:
  - Worcestershire
  - South Staffordshire and
  - Warwickshire



The largest proportional rises being predicted in rural areas<sup>3</sup>

- 3.4. The Alzheimer’s<sup>4</sup> Society estimate that the total annual cost per person living in the community with:
  - with mild dementia is £16,689
  - with moderate dementia is £25,877
  - with severe dementia is £37,473

Of these figures 72% of the above estimated cost is unpaid care provided by family and friends, 28% by Social Care based services.

<sup>3</sup> West Midlands Observatory: Dementia Prevalence table for West Midlands 2011

<sup>4</sup> Dementia 2010 The Economic burden of Dementia and associated research findings: University of Oxford for the Alzheimer’s Research Trust p24.

Living Well with Dementia – A National Strategy<sup>5</sup> reported the following waits in respect of diagnosis:

- people wait up to three years before reporting symptoms of dementia to their doctor
- 70% of carers reported being unaware of the symptoms of dementia before diagnosis
- 64% of carers reported being in denial about their relative having the illness
- 58% of carers believed the symptoms to be just part of ageing
- Only 31% of GP's believed they had received sufficient and post qualifying training to diagnose and manage dementia.

The Prime Minister in March 2012 announced a multilateral approach to tackling what he saw as the UK's "Quiet Crisis"<sup>6</sup>, committing increased efforts and resources into improving health and social care, public awareness and involvement, and stepping up research into the causes of Dementia.

This government action led from the office of the Prime Minister has coincided with reports from the All Party Parliamentary working group into dementia, refuelled the public debate and focussing attention back to the need to take forward the National Strategy. New cash is now promised plus questions asked by the ADDP as to how effective previously allocated spend has been and what changes this has made to people's lives.

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<sup>5</sup> Living Well with Dementia, A National Strategy Department of Health 2010

<sup>6</sup> Department of Health 26 March 2012 Prime Ministers Challenge on Dementia

## 4. More Effective and Responsive Services:

4.1 Findings from local research undertaken by (OCT) 7 across designated pilot sites indicated specific issues for staff, these were:

- A need for an in house dementia specialist to provide support to tenants, and staff
- A need to provide staff with dementia training programme which will encompass dementia awareness through to specialist areas, This will enabling staff to deal with enquiries and emergencies in a useful and sensitive manner.
- Activities to be broadened to encompass informal presentations, activities, written material and promotional material in the local community.
- Development of wider partnerships with statutory, voluntary and community based organisations specialising in Living Well with Dementia.
- Building on and strengthening the positives attitudes of staff working within the organisation.

4.2 Issues emerging from findings indicated that:

- The reality of customers with dementia poses a challenge for OHE, in particular when tenants previously well and independent become ill requiring increased levels of support, security and monitoring.
- Confusion and memory loss are a worry for individuals and their families.
- Customers, their families and their carers do not ask for information as they are unsure of what to ask for.
- OHE staff and customers/families need to understanding that customers at the early stage of diagnosis will not receive support or services from statutory agencies
- There is a need for OHE to be proactive in developing protocols and procedures to assist staff in problem solving, in particular there needs to be a well-established safeguarding pathway with links to key workers from the LA safeguarding teams.
- There is a need for independent advocacy when disputes occur.
- The right type of home and community environment and support with some simple design and layout changes should enable a customer to live 'at home' longer with dementia.
- A programme of intervention for dealing with dementia is necessary
- OHE has an obligation to positively impact on the health and wellbeing of customers living with dementia by promoting dementia awareness, presenting more positive images and reducing stigma.
- OHE in delivering support will need to form working partners such as voluntary/community groups such as Alzheimer's, Age UK, Carers support services,
- People are not currently seeking advice with something as trivial as forgetfulness and are unsure of where to go to and what type of advice is available.
- Use of Technology, aids and adaptations to the home environment are essential in maintaining safety to customers with dementia and their neighbours

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<sup>7</sup> Linda O'Sullivan 2012 A Way Forward: Dementia Issues in OHE Sheltered Schemes

- OHE need a system of recording changes in behaviour and what interventions were undertaken
- Customers with dementia referred to health and social care will be assessed based on the national 'Fair Access to Care services' criteria which also includes a financial assessment.
- Reductions in LA grants and payments to both providers and customers due to continued austerity measures across central government and local authorities will at some point impact on the type and volume of support services purchased and delivered.

#### 4.3 Improvements need to be:

- Dementia aware staff that are well supported by management
- Establishment of communication with the customers wider family and GP
- Development of a dementia based activity programme
- Environmental changes such as changing colour of walls, doors placing furniture strategically can have a big impact on dementia customers.
- Encouragement of customer memorabilia to positively promote wellbeing
- Better partnership working
- A pooling of resources to enhance activities in areas where there is common interest
- Prevention policies to ensure delayed diagnosis does not occur
- Readily accessible good quality dementia information,
- Homes being tailored to the individual's needs.
- Clear lines of communication with health and Social Care when dealing with customers with dementia.

4.4 (OHE) pride itself in its close working links with local agencies and have a good reputation locally as both an independent, specialist housing provider and a key player in delivering public services. (OHE) recognise that in implementing a dementia strategy they must engage and work alongside voluntary and community organisations, for example making community rooms more available and encouraging the wider community into their schemes. OHE acknowledge within this that there may be resistance at times from customers who may object to members of the community using their 'home'.

#### 4.5 Community Hub developments:

The concept of 'Community HUBS', a bringing together of partners through a co-location of services recognised a need for rationalisation of services in a single locality. (OHE) needs to consider the broader aspects of the Localism Bill and closer neighbourhood working in developing services and getting more from their buildings and subsequently enhancing the lives of their customers; this is also the ethos of the government's promotion of 'Big Society'.

A common factor of 'Community HUBS' is their ability to centralise a number of services. They are primarily run by volunteers and can facilitate groups or sessions based around a café model at low cost.

#### 4.6 Access to research and accessible data:

To secure an 'early win' with staff a web based resource directory is attached. (Appendix 1). This can be used by OHE as:

- a basis for improving and developing local resources,
- to assist staff and managers across the breadth of the organisation until local protocols are developed
- as a reliable development aid and
- as a source of advice and information that can readily be made available across OHE for use with staff, customers and their families until local based resources are developed with partners.

## 5. Conclusion and Next Steps:

5.1 **In developing** a 5 year National Dementia Strategy, the government acknowledged that it would only make a difference to people with dementia and their carers/families if it was implemented.

As a leading provider in Older Persons Living (OHE) in developing this strategy are demonstrating their commitment to meeting the government's dementia agenda. As an organisation it appreciates:

- in delivering this strategy it is essential to engage with other agencies with a shared interest of improving services for customers with dementia.
- the benefits and challenges posed and embrace the need to bring together various services to provide for its customers a unique, new and innovative approach to sheltered housing, 'Living Well with Dementia' related service provision.
- that in coming together and focusing on a common goal, a shared vision can be formed with partners of what can be achieved and how to achieve it.

5.2 **In implementing** this strategy (OHE) will attempt to engage with older age and dementia based partners. By bringing willingness to joint work and a resource base to table (OHE) are acknowledging that in developing a shared vision and agenda prospective partners are more likely to be willing to engage.

(OHE) acknowledge both the cost and commitment needed in developing dementia specific services locally and see that economies of scale can be achieved if service providers pool resources, effort and management time. Working in partnership will however take longer, cultural differences will need to be worked through, trust built, and customer's views sought and agreed if delays or sabotage are to be avoided.

This strategy then becomes not just for (OHE) use but will withstand community scrutiny in that its product will effect change locally, both within and outside of the organisation, improving the lives of its tenants and in doing so reducing social isolation and the stigma attached with dementia.

5.3 **In taking forward** this 'Living Well with Dementia' strategy (OHE) will need to:

1. Develop with partners a detailed 3 year 'Living Well with Dementia' implementation plan
2. Nominate or recruit a Lead 'Living Well with Dementia' person
3. Consult with key stakeholders including statutory, voluntary and community sector partners, tenants, their families and the communities in which they live on the 'What, When and How' of the 'Living Well with Dementia' implementation plan.
4. Develop and agree actions, budgets and timelines for achieving the performance targets set for introducing and implementing the 'Living Well with Dementia Strategy'.



## Alzheimer's Society national services

Alzheimer's Society provides several national services and resources to support people affected by dementia wherever they live in England, Wales and Northern Ireland. These complement the many dementia services run locally by Alzheimer's Society. You can find services in your areas online by visiting [alzheimers.org.uk/](http://alzheimers.org.uk/) local information.

## National Dementia Helpline – 0300 222 1122

The Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations. The Helpline is open 9am–5pm Monday–Friday and 10am–4pm Saturday and Sunday. You can also email the Helpline at [helpline@alzheimers.org.uk](mailto:helpline@alzheimers.org.uk)

## Talking Point online forum

Talking Point is the largest online community for people affected by dementia. It's somewhere people can share their experiences, ask for advice, join in discussions and feel supported. Talking Point is available 24 hours a day, every day of the year. Visit [alzheimers.org.uk/talkingpoint](http://alzheimers.org.uk/talkingpoint)

## Information

Alzheimer's Society produces a wide range of information for people with dementia, carers, family and friends. You can access this information online at [alzheimers.org.uk](http://alzheimers.org.uk). Call the Helpline on 0300 222 1122 to request printed materials.





## Our Mission Statement

*We are committed to helping and supporting vulnerable people to establish and sustain their well-being and quality of life. We do this by working with our partners, by building confidence in those we support and by accessing resources that can help facilitate lasting change.*

*We are the small charity that makes a big difference.*



The small charity that makes a **big** difference.

*Registered Office: 5 Daly Avenue, Hampton Magna, Warwick, Warwickshire CV35 8SE*