

**Proposals for the replacement
of six residential care homes in
Cumbria:
A Service User Consultation**

Shaping Our Lives

May 2008

Dr Fran Branfield

Contents

Acknowledgements	page 4
Introduction	page 5
Key recommendations	page 6
Overall Summary	page 9
• Summary of public responses	
• Summary of responses from residents	

Section One: **page 12**

Setting the Scene

1. The National Picture: Promoting change in older people's services
2. The Local Plan for Change: Improving services, maintaining standards
3. A Move to Care Homes with Nursing Care ('Dual registration' homes)
4. Other Local Consultations: Informing, listening and involving?

Section Two: **page 26**

Public consultation through questionnaires

- Introduction
- Summary
- What people told us about:
 - Existing homes
 - Plans for 'dual registration'
 - The perfect home
 - Making the move successful

Section Three: **page 44**

Consultation with residents

- Introduction
- Summary
- What people told us:
 - What do you like about your home?
 - A meaningful life
 - The plan for new homes
 - 'Dual registration'
 - The move
 - The perfect home
 - Support to stay in your own home
- EMI units – observations

Acknowledgements

Shaping Our Lives would like to thank all the residents of the homes for taking part in this consultation; for giving us their time and thoughts about where they now live and the proposed plans for Cumbria Care in the future. We would also like to thank them for welcoming us into their homes so warmly.

We would like to thank the staff at the homes we visited for their support and general good will.

Thanks are also due to Cumbria County Council for asking us to undertake this work and in particular to Peter Woodhouse.

Finally we would like to acknowledge the help and support offered by the two consultants, Ann Macfarlane and Michelle Kershaw who worked with Shaping Our Lives in carrying out the group discussions and interviews, and William Purcell and Jenny Willis for their support in compiling the report.

Introduction

In late 2007 Shaping Our Lives was commissioned by Cumbria County Council to undertake a consultation with service users at six residential care homes in the county. The six homes are the first of the 33 Council run homes to be included in the Council's modernization plan. A consultation document with details of the plan and a questionnaire for responses was distributed to residents, relatives and staff at each of the six homes and to the general public. This report is based on responses to that proposal from service users at the six homes and from other stakeholders who responded via the questionnaire.

The Report is divided into three sections; the first concentrating on the wider picture and outlining the changes in service provision for older people nationally, it then locates this Cumbrian consultation within the national framework. The report provides a brief history of 'dual registration' before looking at other local examples of consultation of this sort.

Section two concentrates on the public consultation, how it was undertaken and the findings. Some residents of the homes completed a questionnaire as well as participating in the interviews. Their views as expressed in the questionnaires are included in this section.

Section three is the central core of this report. In this section we hear what current residents of the six homes think and feel about the council's proposals for change in the provision of their care services.

Key Recommendations

These recommendations are based on what respondents to the public consultation and older people living in the six residential homes have said in the course of the consultation process which ran from 28th January to 28th April 2008.

It is important to make a general point first. Participants in this research recognized the need for change, and that the residential provision in Cumbria cannot continue in its present form in the longer term. It is in this context that participants were broadly positive about the Council's proposals for the replacement of the six residential care homes as part of its modernization plans. There was a remarkable degree of agreement and consistency in what people told us and in what people would like to see included in the modernization plan for the homes.

These recommendations reflect important indicators about how things need to be different, but they equally highlight vital aspects of the current homes which need to remain the same.

Residents, including those in the EMI (Elderly Mentally Infirm) units, value the 'homely atmosphere' of the homes as they are now. Any new homes should attempt to replicate this through:

- Keeping the size of the homes as small as possible
- Designing the new homes around small units
- Ensuring the staff can move with the home

It is important for residents to maintain contacts with the local community and a new home located within the local community is what residents want, and feel is the best way to do this. Residents like to see people 'going about their everyday business'; it makes them feel part of the 'outside world'. This is crucial for a sense of well being and inclusion. All homes currently benefit from central locations. Any move away from this was strongly opposed by both residents and respondents in the public consultation. We recommend that the modernization plans go

ahead only in areas where a central location can be assured.

Most of the older people we spoke to value the company of others. Homes need to be designed to facilitate this. So, for example, having seating outside the home where passers by can stop for a chat; a number of small seating areas for residents to meet with others as well as a lounge area.

Attention needs to be paid to what residents can see from the home, a sports field or playground, for example, provide residents with much interest.

Food and refreshments provide a focal point and structure to a resident's day. Many residents spoke favourably about the food at the current homes and expressed fears about the quality of 'mass catering' in larger premises. We recommend that food continues to be prepared on site.

There is some confusion about what 'en suite' means. For some residents this was a cause for concern as they thought it meant they would no longer receive the support they needed with personal care. We recommend that time is given to individual residents to talk through concerns and identify misunderstandings of this nature.

Residents need more information about 'dual registration'.¹ Most residents were happy with the thought of 'dual registration' but it was clear that this was only so long as the nursing section was separate and distinct from the residential area. As people felt very strongly about this we recommend that the council ensures this is taken into account in the design and organisation of the new facilities.

Residents were clearly upset by the thought of a move to a different home. Two recommendations were made by residents to help allay these fears:

¹ The term 'dual registration' is understood to mean a home which can provide both nursing and personal care for residents and this is how we use the term in this report. However, the term is no longer strictly applicable as all types of homes are now registered only by the Commission for Social Care Inspection (CSCI) rather than with both local and health authorities. Homes are now coded by CSCI as PC for residential homes or N for homes where nursing is provided.

- Staff reassure residents that they will all be moving together
- Some residents visit the new home prior to the move.

The majority of the residents we spoke to and the respondents to the public questionnaire recognize, appreciate and value the important role the staff play in the resident's well being. We recommend that staff are fully included in further developments of these plans. Proper consideration needs to be given to staffing levels to ensure care provision is not compromised.

Residents and respondents to the public consultation have realistic and achievable ideas of what they would like to see in a 'perfect home'. We recommend that all stakeholders are given the opportunity to become more involved in the planning and design of the new homes.

Resident's access needs should be taken fully on board in the design of a new home. For example: electronic doors; appropriate lighting; parking for mobility scooters; hearing loops and width of corridors.

The Council should learn from a variety of other providers to see what has been successful and which pitfalls to avoid in the design and organisation of new homes.

The Council should look at other services they provide to their general population and see if they could also be offered to the residents. For example, mobile library services, access to swimming pool and other leisure activities, education and transport.

The Council to make it clear to stakeholders how these plans for replacing residential care homes relate to its wider policies and proposals regarding home care and extra care sheltered housing etc.

Overall Summary

Summary of public responses:

The vast majority of respondents were positive about the idea of new 'dual registered' homes. They were also happy with current care provision. They wanted things to improve without compromising the way things are.

People said that what made them happy about the present homes were often intangible or emotional qualities such as 'friendliness', the 'caring' staff and the 'feel' of the current homes. In contrast many of the aspirations for the new homes centred on tangible qualities such as en suite bathrooms and more physical space. The challenge laid down by the responses is how the positive aspects of the present homes, and the proposed new ones, can be brought together. Several respondents gave answers to this too, for example by requesting that the small units of the present homes and the benefits of a town central location be retained in the new homes.

Respondents also want to be involved in the whole process of designing and building the new homes or think that there should be mechanisms set up to do this. This should include residents, families, friends, staff and local people.

Overall the people who responded to the public consultation are supportive of the Council's plans. It is clear that they are equally committed to being more than passive observers of change. They want to be part of it.

Summary of responses from residents:

Residents were broadly supportive of the Council's plans. Within this the following issues had particular significance:

Residents, including those on EMI units, like their home to 'feel homely'. For residents the key to this is:

- having friendly and helpful staff

- keeping the size of the home relatively small

To have a meaningful life residents, including those on EMI units, need the opportunities to enjoy the company of others. This can be fostered by having:

- an active activities and events programme
- a day centre on site
- spaces within the home for people to meet

For some residents of EMI units these are important:

- easy access to the garden and safe spaces to walk
- one to one attention from staff
- pets on the unit

Most residents want a meaningful community life.

This can be fostered by:

- Encouraging links with the community i.e. coffee mornings, church concerts, school plays.
- Siting the home in the community so residents can see 'the world going on'
- Having local homes so people remain in the community they have always been a part of

There is a lot of concern amongst residents about the location of the proposed new homes. This is particularly evident in Wigton but also present in the other homes. The concerns focus on:

- The homes being isolated and cut off from the community
- It being harder for visitors to 'pop in'
- Residents will no longer be able to use local amenities
- The new location will cause difficulties for staff

There is some opposition to change although most residents would welcome larger rooms, wider corridors and en suite facilities. Residents are concerned that if the homes got bigger they could lose their 'homely atmosphere'. This equally holds true for residents of EMI units.

'Dual registration' is, for most residents a good thing. However this is only true if the nursing section is quite separate and distinct from the residential side. People thought it would be depressing to be surrounded by ill patients and if they themselves

were taken ill they felt it would be more appropriate to receive nursing care in a separate wing. Some said that by going to a separate nursing wing they would be able to keep their dignity. Residents also feared that the homely atmosphere for residential clients would be lost if the nursing and residential services were not provided as two distinct units.

For many residents the thought of moving is upsetting. To make it easier residents recommended a visit to the new home prior to the move. They also felt staff should reassure residents that they would be all moving together.

Residents had many ideas for an ideal home. These included: accommodation for guests, accommodation for married couples, better use of outside space, meeting of access requirements and more information about their rights and entitlements. Most residents thought a shop in their home would be a very good idea.

It appears that many residents do not have information about domiciliary support services and some were unhappy that they had to move from their own homes.

Section One: Setting the scene

Care should be informed by the principle that care homes are first and foremost places for living rather than like hospitals for receiving care²

You cannot separate out good design, effective management and user involvement...If you do you're left with bricks and mortar, sterile consultancy and nodding platitudes³

there is no substitute for local knowledge and working with individuals and groups in this area is a vital component of planning any future provision⁴

Cumbria County Council's Proposals:

In January 2008 Cumbria County Council announced proposals to build six new care homes which in addition to providing residential care would also offer nursing care. These 'dual registration' care homes (now known as 'care homes with nursing') will be built between 2008-13 in partnership with Cumbria Primary Care Trust. Six care homes which only offer residential care will close once the new facilities are completed. The aim is to provide integrated health and social care services on the sites of local Community Hospitals or an alternative nearby site.

Proposed Locations:

Wigton, Keswick, Brampton, Millom, Alston, Penrith.

Rationale:

Cumbria County Council states in its consultation document that Cumbria's homes do not meet modern

² J Reed et al, *Settling in and Moving On*, in Bill Bytheway ed, *Understanding Care Welfare and Community*, (2002) Routledge, p81

³ Cantley C and Wilson R, *Put yourself in my place – Designing and managing care homes for people with Dementia*, (2003) Joseph Rowntree Foundation, p93

⁴ Hirsh, D, *Understanding the expectations of Older People*, (2007) Joseph Rowntree Foundation, www.jrf.org.uk/older-people/documents/overview.pdf , Last visited 14/4/08

standards and that leaving the homes as they are is 'simply not an option'. Therefore the consultation is premised on the basis that the older homes will be replaced, while trying to ensure that the new homes keep what is already good about the current residential homes.

1. The National Picture: Promoting change in older people's services

For the last decade the issue of service provision for older people has been prominent on the political agenda and is currently the subject of a Government Green Paper. In October 2007 Alan Milburn MP described the Government's current position,

...In last week's Pre Budget Report, the Chancellor announced our intention to develop a Green Paper on Social Care and Support, with a particular focus on older people... Over the coming months, we will lead an extensive consultation to fully explore the issues and options which lie ahead: but what is absolutely clear is that, in the face of profound demographic, technological and social change, this is an area that requires radical thinking and where the current arrangements are unsustainable...⁵

The Cumbria County Council consultation is borne out of earlier Government initiatives to improve the quality of older people's services in particular the National Service Framework.

a) National Minimum Standards – Room Size.

The National Service Framework for Older People ('NSF') established in March 2001 set out to ensure "fair high quality integrated health and social care services for older people..."⁶.

⁵ Speech to the Local Government Association/Association of Directors of Adult Services Annual Conference, by Rt Hon Alan Johnson MP, Secretary of State for Health, 18 October 2007: 21st century compassion, Last modified date: 25 October 2007, http://www.dh.gov.uk/en/News/Speeches/DH_079680 , Last visited 18/2/08

⁶ Department of Health (2001), National Service Framework for Older People, p5

Regulations to enforce national minimum standards in Care Homes across the country are now in their 3rd edition ⁷ following the introduction of the Care Standards Act 2000. They 'focus on achievable outcomes for service users' ⁸ and provide the framework for inspection of care homes by the Commission for Social Care Inspection. In particular the Regulations set out minimum space requirements for service users in 'Standard 23.2' which requires there to be '12 square metres of usable floor space' ⁹ in each bedroom in newly built or registered premises. In pre-existing homes (prior to 2002) this standard does not apply as long as the usable floor space in each bedroom is not reduced (Standard 23.3).

The National Minimum Standards also require the provision of en suite facilities (at minimum a toilet and hand basin). The six Cumbria County Council homes in the consultation do not meet the minimum space requirement or requirement for en suite facilities but equally they are not required to in the way that any new homes will be. The standards do not stipulate a minimum number of rooms for couples, imposing instead a requirement that there be no reduction in the percentage of single room provision and that providers 'make clear which clientele their homes are aimed at' ¹⁰.

It should be noted that while homes that have been registered since before 2002 are not required to meet the standards discussed, the fact that they may not does affect the quality of care offered to residents. Practical difficulties can be faced by staff providing care in confined spaces when operating hoists, wheelchair users face difficulties in navigating narrow corridors and manoeuvring in small rooms and the lack of en suite facilities, while tolerated by

7 Department of Health (2003), Care Homes for Older People – National Minimum Standards and the Care Home Regulations 2001

8 Department of Health (2003), Care Homes for Older People – National Minimum Standards and the Care Home Regulations 2001, p viii

9 Department of Health (2003), Care Homes for Older People – National Minimum Standards and the Care Home Regulations 2001, p24

10 Department of Health (2003), Care Homes for Older People – National Minimum Standards and the Care Home Regulations 2001, p20

many residents currently in homes, would be less likely to be tolerated by those who may need to access residential care in the future.

b) National Minimum Standards – Integrating services.

The government wants to see an integration of services for older people. The NSF prescribes that these services should be developed through local strategic partnerships between councils and health authorities and highlights the need for involvement of service users throughout,

...Translating the national standards in this NSF into new and better services for older people will be achieved through local arrangements which:

- listen to and act on the views of older people and their carers...¹¹

The new facilities to be developed in partnership between Cumbria County Council and Cumbria Primary Care Trust are designed to provide these 'integrated' services. They seek to address the NSF's principles of 'Person Centred Care' and 'Intermediate Services' which are designed to enable service users to 'make choices about their own care', to 'promote their independence' and 'prevent premature or unnecessary admission to long term residential care' ¹².

Cumbria County Council's proposals to site new care homes in the grounds of Community Hospitals (or alternative nearby sites) is part of this national drive for service integration. In 2006 the Department of Health White Paper 'Our Health, Our Care, Our Say' outlined a move towards reinvigorating the Community Hospital sector,

...we will over the next five years develop a new generation of modern NHS community hospitals. These state-of-the-art centres will provide diagnostics, day surgery and outpatient facilities

¹¹ Department of Health (2001), National Service Framework for Older People, p115

¹² Department of Health (2001), National Service Framework for Older People, pps12-13

closer to where people live and work...These will be places where a wide range of health and social care services can work together to provide integrated services to the local community...¹³

Cumbria County Council's plans accord with the government's desire for 'plurality of provision'¹⁴ through local partnerships between PCTs, local authorities and the voluntary sector to 'co-locate'¹⁵ services to provide 'one-stop shops'¹⁶ for health and social care services. The homes would help provide a clearer 'care bridge' between residential/nursing home care and hospital. This so called 'step up' and 'step down' care is aimed to improve the recovery outcomes for service users going into and out of hospital.

c) Involving Older People in Decision Making:

Crucial to this national and local change is the greater involvement of older people in designing and delivering services. This approach is reflected across Government. The Government White Paper reiterated the importance of partnership with the local community to ensure that,

...local people are engaged from the outset in identifying opportunities, challenges and options for change. The need for change should be explained clearly and reconfiguration processes should be swift and effective. It is important that the local community feels a real sense of involvement in and ownership of the decision...¹⁷

The Department of Work and Pensions said in 'Opportunity Age'¹⁸,

13 Department of Health (2006), Our Health, Our Care, Our Say, p143, <http://www.official-documents.gov.uk/document/cm67/6737/6737.pdf> Last visited 27/2/08

14 Department of Health (2006), Our Health, Our Care, Our Say, p145

15 Department of Health (2006), Our Health, Our Care, Our Say, p145

16 Department of Health (2006), Our Health, Our Care, Our Say, p146

17 Department of Health (2006), Our Health, Our Care, Our Say, p149

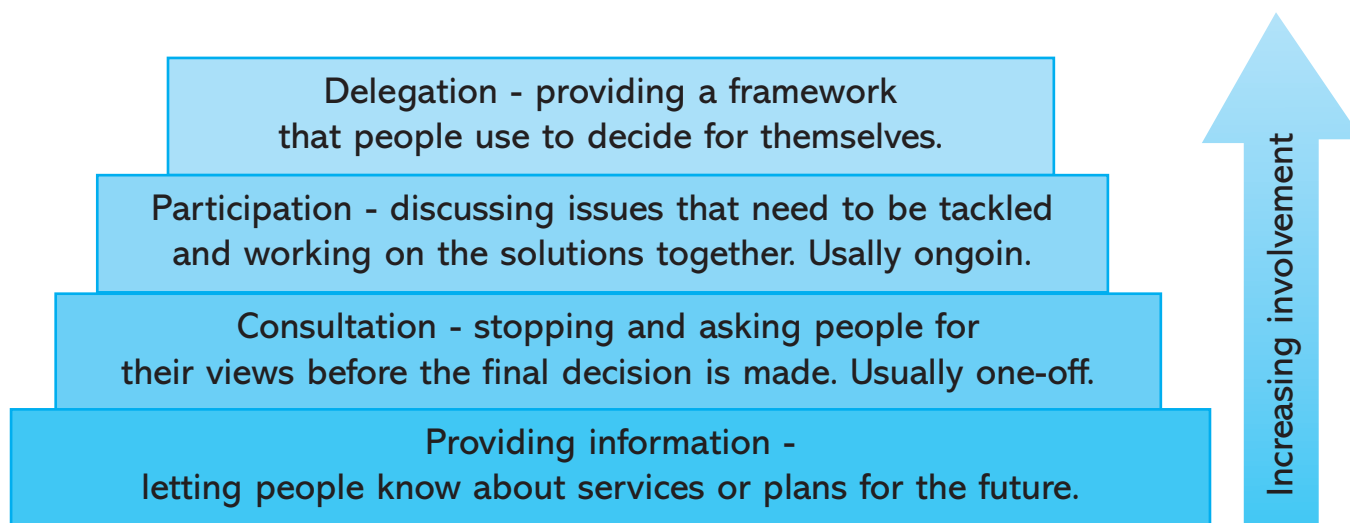
18 Department of Work and Pensions (2005), Opportunity Age, p68, http://www.dwp.gov.uk/publications/dwp/2005/opportunity_age/opportunity-age-volume1.pdf Last visited 26/2/08

...We want to achieve a society where increasingly diverse older people are active consumers of public services, exercising control and choice, not passive recipients of them. This requires a culture change, both by individuals and providers...

In 2004 The Audit Commission published 'Older People – Building a Strategic Approach' which argued that:

...New approaches to older people that focus on well-being, independence and citizenship must be based on the involvement of older people as central partners and contributors...[such] a broader approach demands that communities move away from traditional consultation methods, often involving a one-off meeting or event, towards longer-term structures and processes...¹⁹

The Audit Commission describes a series of stages in user involvement which are vital to working towards achieving this deeper engagement:²⁰



The report provides detailed evidence from study sites to support their contention that this

¹⁹ The Audit Commission (2004), Older People – Building a Strategic Approach, p15, http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/E7EB90FE-1DE9-4D09-B0E6-897A7E0EE46D/OlderPeople2_web_2.pdf Last visited 26/2/08 - The report sets out detailed examples of good practice in older people's involvement and outlines aspirational guidelines.

²⁰ The Audit Commission (2004), Older People – Building a Strategic Approach, p13

empowered, ongoing partnership with service users is essential in ensuring a sustainable improvement in care services.

Both the Government and the Commission for Social Care Inspection are intent on transforming social care for older people by putting 'people in control'²¹ .

The Chief Inspector of CSCI Paul Snell re-iterated in November the central importance of service user involvement in this process,

...Making 'quality care' a reality for every older person who uses care services means paying attention both to the big things – the policy framework that provides the context in which care takes place – and the so-called 'little' things – the day-to-day things that really make a difference to people's lives. It means taking as our starting point what people who use services tell us they want...²²

In January 2008 the CSCI published its annual report 'The State of Social Care in England 2006-7' and echoed this theme by stating that the key aspirations of the Government include ensuring that,

...People have the opportunity to exercise choice and control, developing their own solutions and support to shape their lives, and the services they require...²³

Cumbria County Council's consultation on their proposals provides advocacy for residents in individual and group processes but is only at the second level of participation outlined by the Audit Commission. The story of the closure of the Bell View residential care home by Northumberland

21 Commission for Social Care Inspection (2008), *The State of Social Care in England 2006-7*, p vii

22 Speech to Laing & Buisson Conference on CURRENT AND FUTURE CHALLENGES IN THE PROVISION OF HOME CARE, by Paul Snell, Chief Inspector, Commission for Social Care Inspection, 6th November 2007, <http://www.csci.org.uk/default.aspx?page=2255&key=>, Last visited 18/2/08

23 Speech to Laing & Buisson Conference on CURRENT AND FUTURE CHALLENGES IN THE PROVISION OF HOME CARE, by Paul Snell, Chief Inspector, Commission for Social Care Inspection, 6th November 2007, <http://www.csci.org.uk/default.aspx?page=2255&key=>, Last visited 18/2/08

County Council should be seen as an example of the possibility of developing positive long term participation with older people. Out of the ashes of the care home came a £1.4m community funded and designed resource centre ²⁴.

d) Growth in the Population of Older People and the shift away from residential care.

The number of people who may require health and social care services is likely to increase dramatically in the next decades. Government statistics show that falling fertility and a decline in mortality have meant that the percentage of people who are 85 years old or more within the 50+ population has trebled since 1951²⁵. In the White Paper 'Our Health, Our Care, Our Say' the government stated that the number of people over 85 who would require residential care would double by 2020²⁶. In the year to mid-2006 the Office of National Statistics recorded the largest growth in the 85+ population to a record 1.2 million people. Perhaps surprisingly there has been a national decrease in the number of care home places (except in rural shire councils ²⁷),

...the overall numbers of older people using services has dropped overall from 867,000 people in 2003 to 840,000 in 2006; and this at a time when the population aged 75 and over increased by nearly 3%... ²⁸

In the North West the number of homes has fallen from 2517 in 2003 to 2227 in 2006. The number of places for residents has fallen from 63,755 to

24 Reed J. et al, Older People 'getting things done', (2006) Joseph Rowntree Foundation, pp14-41

25 In 1951 the percentage of people 85 or over within the 50+ population was 1.6%. In 2003 it was 5.5%. www.statistics.gov.uk/focuson/olderpeople Last visited 10/2/08

26 Department of Health, Our Health, Our Care, Our Say, p16, <http://www.official-documents.gov.uk/document/cm67/6737/6737.pdf> Last visited 26/2/08

27 Commission for Social Care Inspection (2008), The State of Social Care in England 2006-7, p45

28 Commission for Social Care Inspection (2008), The State of Social Care in England 2006-7 Executive Summary, p9

61,448 in the same period ²⁹. This is partly a result of bringing care 'closer to home' through telecare and other 'assistive' methods of support for older people in their homes and also through extra care housing. However the fall in provision has increased concern about people who do not manage to access social care from Local Authorities and so are 'lost to the system'³⁰.

According to the Joseph Rowntree Foundation ('JRF'), Government policy has been instrumental in the downward trend in care home places,

'...some decline in care home provision between 1991 and 2001 was as expected given the policy objective of the 1990 NHS and Community Care Act. The Act sought to encourage a much greater diversity of community care provision and to end the growth of residential social care...' ³¹

This diversity of provision has meant an increase in 'Housing with Care' or 'Extra Care Sheltered Housing' developments and 'Continuing Care Residential Villages'. Users of these new services value the sense of independence and security they enjoy. However they cannot replace residential care. Joseph Rowntree Foundation research suggests that there are limits to the ability of housing with care to replace residential care,

...housing with care can provide an alternative to residential care for some people in some circumstances, but the numbers of people moving on from housing with care into both residential and nursing homes indicate that housing with care is not always a substitute...³²

29 Social Care Provision in England and Wales, Provision by Region - Historic Data, www.csci.org.uk, Last visited 26/2/08

30 Commission for Social Care Inspection (2008), *The State of Social Care in England 2006-7*, p xi and pp154-5 e.g. 'Situations were uncovered where the absence of any help, or the provision of inadequate help, resulted in very poor individual experiences.'

31 Banks et al, *Changes in Communal provision for adult social care 1991-2001*, (2006) Joseph Rowntree Foundation, www.jrf.org.uk/ebooks/multi/01-9781859354865.pdf

32 Croucher et al, *Housing with care for later life. A literature review*,

However the positive aspects of these new forms of housing are potentially applicable across all social care provision. Karen Croucher's research for the Joseph Rowntree Foundation describes the factors service users like about extra care housing,

...Having your own front door was a key feature of residents perceptions of independence, but other aspects of the schemes – such as barrier-free, purposefully designed, warm environment, positive philosophies of care that emphasised the maintenance of skills and abilities, whether or not to prepare your own food or eat in the dining room, having guests to stay, were also integral to promoting independence...³³

Residents in retirement villages are similarly positive about their experience,

...the evidence we do have indicates the great potential of retirement villages to expand the choices of living arrangements for older people – offering the opportunity not just for decent age appropriate housing but also for enhancing older people's quality of life, health status and sense of well being and security...³⁴

Cumbria County Council's proposals for care homes that would provide nursing care do not include discussion of sheltered and extra care sheltered housing, nor retirement villages. However the positive feedback from service users about what they want and like from such services is based on factors that are applicable across the spectrum of care provision and should be taken into account in designing the new services.

(2006) Joseph Rowntree Foundation, www.jrf.org.uk/bookshop/ebooks/9781858354384.pdf

33 Croucher et al, Housing with care for later life. A literature review, (2006) Joseph Rowntree Foundation, p94, www.jrf.org.uk/bookshop/ebooks/9781858354384.pdf . Last visited 14/4/08

34 Croucher, K., Making the case for retirement villages, (2006) Joseph Rowntree Foundation, p19 www.jrf.org.uk/bookshop/ebooks/9781859354650.pdf . Last visited 14/4/08

2. The Local Plan for Change: Improving services, maintaining standards.

The Commission for Social Care Inspection reports ³⁵ set the local picture of social care services within the National Framework. Their inspections of the six homes within the current consultation show what is good about the homes from a national perspective and also gathers feedback from the residents. The inspection reports all took place within the last two years,

Inglewood (Wigton) – 31/8/06 / Ravensfield (Keswick) - 26/4/07 / Moot Lodge (Brampton) - 21/8/07 / Lapstone House (Millom) - 13/4/07 / Grisedale Croft (Alston) - 7/11/06 / Greengarth (Penrith) – 23/5/07

Key Findings:

a) Resident Satisfaction High:

In all the homes the residents were very satisfied with their accommodation and the care that they received from the Cumbria Care staff.

b) CSCI Inspectors satisfied with the standard of care:

With the exception of Greengarth which although much improved still required further work (e.g. social and leisure activities, décor and furnishing, staffing) each home received considerable praise from the inspectors. Grisedale Croft was 'warm and homely', Inglewood was described as 'a nice, friendly, family type home', Lapstone House provided 'excellent' personal and health care and 'excellent varied and changing interests and activities'.

c) Room sizes small but adequate:

Room size was consistently noted as smaller than National Minimum Standards for new residential care homes. Accommodation was therefore graded as 'adequate' (Inglewood and Greengarth) or 'small'

³⁵ www.csci.org.uk

(Grisedale Croft, Moot Lodge, Ravensfield). The Inspector at Moot Lodge noted that in spite of this limitation on space residents were 'very pleased' with their accommodation. There is no evidence in the reports that any residents were dissatisfied with the size of their rooms.

d) En suite accommodation limited and no double rooms for couples:

There are no double rooms in the six homes that are part of the consultation process and none of the reports address any demand for such provision. There are also only a handful of en suite bathrooms. Again there are no recorded comments from residents about this. The Cumbria County Council consultation states that new facilities would include rooms for couples and en suite bathrooms as standard.

3. A Move to Care Homes with Nursing Care ('Dual Registration' homes).

Dual Registration of homes became possible after the Residential Homes Act 1984. Homes were permitted to register under section 1 as a residential care home and also under section 21 as a nursing home. Critics of the preceding regime such as the Joseph Rowntree Foundation had argued for a single registration scheme to allow for flexibility of care within homes. The rationale for ending the distinction in care levels was that the system created a two-tier care service which according to one group of researchers provided a

...fragmented experience for older people when and if their needs change...³⁶

The National Care Standards Commission (Registration) Regulations 2001 reflected this criticism and care homes are now registered with the CSCI and agree with them what types of services

³⁶ J Reed et al, *Settling in and Moving On*, in Bill Bytheway ed, *Understanding Care Welfare and Community*, (2002) Routledge, p81 - Interestingly they also argued that the separation of nursing and residential care within the same building risked a similar disruption to older people moving from one level of care to another.

they will provide. If the care provider wishes to provide care and nursing services then they are registered as a “care home with nursing” and can provide flexible levels of care within a home, so reducing the disruption caused by moving older people whose care needs have increased.

In Cumbria the local authority has no nursing homes and so at present cannot address this potential for disrupted care as service user needs change. There is also a competitive issue within the county where Private and voluntary providers run 36 homes with nursing care ³⁷. The county council is unable at present to provide a number of services which future (if not present) residents may wish, and which may determine their choice of care provider.

4. Other Local Consultations: Informing, listening and involving?

The following are two examples of recently undertaken consultations on similar issues:

Camden – Serving Older People – Consultation in January 2007 to replace four residential homes.

London Borough of Camden consulted on the future of its four residential care homes providing care for 188 service users. It proposed to close these homes and build two new ‘care homes with nursing care’ for 120 residents each and to increase extra care housing provision on the same sites where possible. Response from consultees was positive (75% overall) although there was notable concern about the location of the new homes. The only reported comments on the change from ‘residential care only’ homes to care homes which also offered nursing were by Age Concern who requested more information and by the Camden and Islington Mental Health and Social Care Trust who said it would enhance ‘continuity of care’. The £30m plans were

³⁷ Regional Care Provision – North West.xls, www.csci.org.uk Last Visited 26/2/08

passed in September and completion of the project is due within five years. Consultation took place at public meetings and on a one to one basis with two consultants employed by the council. Responses were collated into a final report although it is unclear in what way they influenced the council's plans which on the face of it were not changed at all ³⁸.

Coventry City Council – Consultation January –April 2008 to close remaining residential care homes as part of long term strategy to increase extra-care sheltered accommodation ³⁹.

This consultation reflects a similar move away from residential only care provision as in Camden. There is however no provision to build new homes. The consultation appears to be one of informing residents and stakeholders of plans rather than of empowering people to influence them.

Derby City Council is also in a process of consultation but again this is a consultation that appears to be determined by a desire to inform rather than constructively engage with older people.

It is hoped that this consultation in Cumbria will go further than either of these examples in involving stakeholders in a meaningful way.

38 <http://www.camden.gov.uk/ccm/content/social-care-and-health/residential-and-nursing-home-care/serving-older-people.en>

39 <http://www.coventry.gov.uk/ccm/navigation/social-care-and-health/social-services/older-people---support-for-the-elderly/older-people-first---have-your-say/older-people-s-services---consultation-on-closures/>

Section Two: Public Consultation through Questionnaires

It is well understood that the buildings no longer meet modern-day requirements and that the good reputation of the current homes is based on the quality of care people receive.

[The home] is well thought of in our town. Residents are happy. The upheaval of moving will be stressful for them. The site is excellent at present being near to the town enabling the more independent residents to go out on their own.

Great advantage that older people would not have to move for nursing care

Think along the lines of a cruise ship's facilities and you'll be spot on. Greater thought given to ventilation and soundproofing. Large fishtanks, nice lighting, views onto bird and red squirrel feeders - areas that encourage people to congregate and that provide talking points. Small theatre space for live and projected performances - air-blown popcorn stand? Wireless internet, satellite TV. hook-ups with education providers for crafts sessions, etc.

Introduction

This section reports the views, opinions and ideas of people who responded to the Cumbria County Council consultation by filling in a questionnaire or contacting Peter Woodhouse directly. The Council made every effort to distribute the consultation document as widely as possible. 8000 copies of the document and questionnaire were distributed through local libraries, social work and occupational therapy teams, Primary Care Trust staff, councillors at County, District and Parish levels, churches and voluntary organizations, equality groups, independent care home providers, housing associations, trade unions, district working group members and

residents, relatives and staff at the six homes concerned. 88 completed questionnaires were received and fifteen letters and emails. This response rate is disappointingly low. One explanation could be that the plans in themselves are not controversial; they do not include a reduction in service provision. The following comment from a Parish Council underlines this:

The Parish Council welcomes the proposals in the consultation document and the upgrading of the named care homes in Cumbria...The Council's only concern is that the number of places available in the care homes should not be reduced.

Equally this low response rate could reflect a more general reluctance to consider making provision for our own old age until it becomes absolutely necessary.

Respondents to the questionnaire could choose to relate their answers to one or more location. The breakdown by location was as follows:

Alston	13
Brampton	7
Keswick	7
Millom	10
Penrith	13
Wigton	23
General	15

The increased responses relating to Wigton may reflect the higher level of concern about the proposed location of the new home.

The number and nature of responses did not lend themselves to statistical analysis. To capture the richness and diversity of what people said we have chosen to use a qualitative methodology.

Summary

The vast majority of respondents were positive about the idea of new 'dual registered' homes. They were also happy with current care provision. They wanted

things to improve without compromising the way things are.

People said that what made them happy about the present homes were often intangible or emotional qualities such as 'friendliness', the 'caring' staff and the 'feel' of the current homes. In contrast many of the aspirations for the new homes centred on tangible qualities such as en suite bathrooms and more physical space. The challenge laid down by the responses is how the positive aspects of the present homes and the proposed new ones can be brought together. Several respondents gave answers to this too, for example by requesting that the small units of the present home and the benefits of a town central location be retained in the new.

Respondents also want to be involved in the whole process of designing and building the new homes or think that there should be mechanisms set up to do this. This should include residents, families, friends, staff and local people.

Overall the people who responded to the public consultation are supportive of the Council's plans. It is clear that they are equally committed to being more than passive observers of change. They want to be part of it.

What people told us

1. What do you like about the existing homes?

– Location

The questionnaire asked people what they thought were the good points of the existing homes. Many respondents said that it was where the current homes were, their location that was important:

Close to the people.

Proximity to hospitals and also to town centres.

Grisedale Croft in Alston is very near to the centre of town so making visiting easier.

Very central (Millom)

Right in the community (Keswick)

The response from Carlisle City Council noted:

The single home, Moot Lodge, Brampton, within the Carlisle City Council area, is in an ideal position being in the centre of the town. Residents, if mobile, are able to visit local shops, GP surgery, hairdressers etc. It also enables relatives, especially children who live locally to visit easily.

This was most noticeable in the questionnaires that related to Wigton:

Inglewood – locality, residents can easily go out for newspapers, church, coffee mornings, Wigton Medical Centre.

The location is good easy for residents to go for a walk or shops, doctors nearby.

This reflected the overwhelming concern with the proposed new home's location on the Wigton Hospital site:

A big disadvantage for elderly people to be taken in a wheel chair across Wigton By Pass road, anyone who uses a mobility scooter would be dicing with death getting into Wigton.

The hospital site is detached from Wigton by the by-pass and is approached (by foot) up a steep

hill, making visits by elderly friends and relatives difficult. The present bus service is almost non-existent. The present Inglewood site is good

Wigton hospital is too far out for the residents.

The same site in Wigton was a common comment from those spoken to in Holme East Wave Parish – local facilities are very much to hand.

It would not be possible for able people to walk down to the town.

Community Hospital in Wigton is very remote.

The hospital is out of town therefore not accessible to local facilities e.g. shops, library.

Many folks won't be able to visit and visiting times don't fit with buses and hospital visiting times, older people don't have cars!

One respondent wrote on behalf of Red Dial Wigton and as chair of Wigton Age Concern. She reported the strong objections to moving Inglewood out of town to the proposed Community Hospital site. These objections detailed the benefits to residents, visitors and the local community of Inglewood's town centre location. These benefits included:

The present home is beside the new surgery...The Church next to the home is well used for services, lunches and coffee mornings...Three schools are nearby [for] visits...Minutes away are two shops and the residents can be wheeled to these, plus the shops in the town are no more than 5 minutes in a wheelchair...By no means least the Town Carnival parades as far as Inglewood and encourages the residents to join in the fun. All this activity would be impossible if the home was out of town.

One respondent did however speak positively about the new location in Wigton,

If built on site by Wigton hospital would be like living in the country, very open aspect, superb.

Why is the location important?

Proximity to people and places within a community such as shops and services makes the homes accessible. It makes it as one respondent put it “Part of the community”.

[Grisedale Croft] is easily accessible. It feels like a home, not a hotel and not a hospital.

Interaction local townfolk calling in – due to the warm welcome (Inglewood).

In Wigton from a social point of view an in town site gives residents contact with the outside world.

We do not consider that there are any disadvantages to developing new care homes, providing they are in convenient, easily accessible sites.

Central location with views onto town centre enabling people to feel part of the community even when not active. Easy access for friends & family. Harder to forget residents when walk past the door.

It is a flat site central to local services. Fit residents can walk into the town centre.

What do you like about the existing homes?

– The staff

The current staff received huge praise for the way they do simple but vital things.

Staff who care about the residents.

Personal care and time spent with residents.

[The]Commitment of the staff

Very helpful caring staff (Alston)

Staff are very caring (Brampton)

Good understanding staff – take time to talk to you (Alston)

The staff being interested in the residents (Keswick)

Staffing, local interaction

They almost all have local people working in them and are nearly always familiar to the clients and their families.

Ravensfield is the only one I know and have known well for nearly 30 years.

There is a marvelous atmosphere of family and home there largely due to their wonderful, caring unselfish staff.

Small units with designated staff. Take a visit to Inglewood and see how they operate. You feel part of an extended family.

The quality of the staff is No1. Friendly well trained staff who genuinely care. (Wigton)

Their work was also praised in spite of the difficulties of their tasks or the circumstances in which they work:

The personal care that makes each resident feel an individual under for some really difficult circumstances.

[T]he friendly caring and often under-resourced staff do all they can to compensate for sadly out of date facilities. (Penrith)

Wonderful staff and ability to adapt and overcome any shortfalls in present accommodation. All residents are treated as family members (Wigton)

There were some concerns raised,

There is some activity provision for residents but this does not seem to be particularly well provided. I'm not aware that residents are able to pursue the free time activities that are important to them (Keswick).

What do you like about the existing homes?

Small units, good food.

Small units are seen as key to creating a friendly and welcoming environment and even a feeling of family in the current homes:

The homely atmosphere of 10 people per unit.
(Penrith)

The flatlets are very good – offering a degree of independence (Alston)

I like the small units – maybe 8-10 in a unit
(Wigton)

Small units reminding people of cosy homes
(Wigton)

Smaller day units (Penrith)

Home cooked food was also seen as important:

Good quality food produced on a small scale
(Penrith)

Good food cooked on the premises (Keswick)

Good quality cooked lunches (Alston)

What do you like about the existing homes?

Summary:

Respondents were almost uniformly positive about the current homes and most responses actually reflected an emotional response, to how people 'felt' about the existing homes. There will be inevitable bricks and mortar changes in the new buildings that are partly demanded by government legislation and will also be informed by the ideas of respondents and other experts. But the opinions from this part of the questionnaire are both subtle and vital. They can be summed up by one of the Inglewood residents who completed a questionnaire:

“Friendly staff – well cared for. Good food – activities, trips to lunch and shops, bowling. Freedom to please myself. Staff to talk to – family – visitors welcome, sit outside in nice areas, good atmosphere, plenty of sun seats - ”

2. What do you think about the plans for new dual registration homes?

Respondents were asked for both their positive and negative views on the idea of building new joint

residential and nursing care homes. The positive aspect of most responses is clear here too. In spite of a widespread concern that change will bring stress and confusion to residents, there is an almost unanimous welcome for the improvements in physical space and amenity promised by the County Council's proposals:

Meeting Local Needs:

Several respondents were very happy that the new homes would fill gaps in local nursing care provision.

I think it is what Millom is in desperate need of.

Great advantage that older people would not have to move for nursing care (Keswick)

Excellent plan, as no nursing care home in Penrith town centre.

Huge advantage for a town like Alston. At present residents needing nursing care are sent away to Penrith or Hexham, thus making visiting very difficult.

I think that dual purpose homes are the way forward as everything on one site makes sense instead of traveling to Carlisle. It also means they stay in the local community. (Brampton)

Patterdale Parish Council noted however that their need for residential or nursing home accommodation which kept people close to their homes was not being met. They suggested that some form of sheltered housing be considered for the Patterdale area.

Similarly Wetheral Parish Council argued that there should be an increase in care services in the area such as domiciliary care teams, a health centre and a District nursing service.

Allerdale Borough Council similarly reflected a concern for domiciliary care to be given proper consideration as part of the County Council's plans:

The allied home care package needs to make sure that an individual's need is catered for. Our Members are concerned at the current provision,

through which people in their own homes are helped to bed at a very early hour, because that is when help is available....inevitably, if the home care package is not achievable, then this will have a direct impact on residential care home capacity.... There would appear to be little in the way of Extra Care housing in the pipeline for Allerdale. This issue clearly needs to step up the agenda under the home care ethos.

Improved Facilities:

Most respondents said that the new facilities would improve residents' quality of life:

En suite bathrooms, space for wheelchair, improved access to a garden (Penrith)

Ceiling hoists from bed to bath and toilet.

Will help when couples need rooms.

Better living conditions for residents; improved homeliness; more dignity and privacy; better access to health services.

Ensuite facilities mean more privacy and dignity for residents, hopefully a less institutional atmosphere.

Not everyone was positive about the new facilities though:

I think there isn't a need to have baths or showers in each room as most people are not fit to bath themselves.

Reduced Disruption to Older People:

The Council's ideas made sense to respondents most of whom could see the advantages of avoiding the stress of 'moving home' when an older person needed nursing care:

Good idea to have a 'one stop shop' available. It can be unexpected and quick to move from residential care to nursing care.

Continuity for people as their needs increase.

On the spot medical treatment

Modern amenities in proximity to healthcare facilities.

Concerns:

There were a few concerns about the impact of providing both nursing and residential care together:

People may drift towards common denominator of higher dependence and health focus.

There are significant cost implications to providing 24 hour waking cover from qualified nursing staff. There is also the potential for clients and their relatives to assume that all residents will have any nursing needs met by the nurses employed in the home. It has to be made very clear to all concerned that only those residents assessed as 'nursing' can have their nursing needs met by the home's nurses.

If it is amalgamated with the hospital...it is not the same homely care.

I do not think it is a good idea to incorporate EMI residents.

There was also considerable concern that the Council would succeed in building larger homes that remained personal. This prompted a large number of suggestions which will be noted in the next section.

Two respondents also reflected a concern that in failing to include sheltered or extra care sheltered housing in the proposals, the Council's vision was not expansive enough to meet the spectrum of services that older people will increasingly demand in the future:

Great idea to develop and future proof all homes but would it not be advantageous to include sheltered housing in the plans – they should be integral to the dual registration concept and could be the hub for some residential/nursing care delivery.

New homes set within a health village concept/style with access to 3rd sector social care/entertainment/leisure.

3. The Perfect Home – What would you like to see in the design of the new care home?

Respondents were asked what they would like to see included in the design of a new care home. This request for ideas prompted a great number of constructive proposals. There were two other questions which offered respondents a chance to express concerns about aspects of the Council's proposals but which generated positive suggestions and solutions which are included below. These are a selection grouped into themes relating to the physical environment of the hoped for new home, the design features that may encourage independence and ideas that are important for wellbeing:

Flexible spaces:

A range of community areas

Small lounge and dining room for set number of residents. Quiet lounge nearby. Large communal lounge with integrated conservatory overlooking garden with nearby access. This lounge to accommodate chairs and wheelchairs for aerobics, carpet bowls, concerts and church services.

Craft and hobby area. Library area.

Raised flower beds.

Exhibition space – stimulate residents – relate to school children tales of life ...and understanding between older and younger people.

Smaller units within the home that will help to retain the feeling of homeliness.

Large enough rooms (obviously en-suite) so that residents are able to bring some of their own small pieces of furniture and other possessions into the home.

Facilities for married/cohabiting couples

Quiet areas both on the units and in communal parts of the home.

Sitting rooms and dining rooms on each unit.

A smoking room – preferably one on each unit.

Appropriately placed communal toilets and bathrooms.

Appropriately placed sluice rooms with mechanical sluice disinfectors.

Larger sitting and dining facilities in communal areas of the home.

Doctor's surgery facilities/treatment room.

I think that if there are going to be different things on a new site it would be good to think about having a recruitment agency for staff and to think about recruiting different people for care work. There are not that many young people here who want to do care work but there are older people who may not have thought of it who could be good. We need to get a wider range of people interested.

Corridors that are either slightly curved or are punctuated with features so as to avoid the perception of them being unduly long.

Adequate storage areas both on the units and in the home as a whole - in particular the amount of space needed for wheelchair and hoist storage is often underestimated.

Home cinema

Swimming pool – small facility – metre deep.

Recreation space, chapel

My focus is on meeting the occupational needs of residents. It is very important that they are able to spend time carrying out the activities that are important to them. This could include a small lounge/activity areas, a space to make a meal, snack, hot drinks, access to computers with assistance if necessary, access to outdoor areas with for example sensory gardens and level access.

Small quiet areas for reading – with no television, recreation areas; older people these days do a lot of different activities.

Small comfy intimate sitting areas not large open spaces with seats all round.

A fire(place) in the leisure rooms

Rooms for private/family discussion.

Please no more circles round a TV. Has anyone ever asked residents if they want that?

I would very much like to see a larger walking place for people with dementia to exercise in.

An area for recreation and stimulation.

Communal facilities open to all the community enabling residents to feel part of the wider community.

Hair dressing salon. Small café area (run by volunteers) where relatives and friends can take residents for a coffee and snack.

Shop for cards, stationary, confectionary and toiletries.

Maintaining Independence:

Residents to have their own 'front door' within the new homes to emphasize their privacy and independence.

Own belongings.

Small flatlet for families who have moved away when they come to visit.

Places for families and friends to make a drink or snack.

Encourage the start of a "friends of..... Home" group for fund raising and activities

Bedsits where people can close their own door, entertain family and allow family to make drinks etc.

Increasing Wellbeing:

Windows placed low down so the residents can see out instead of looking mostly at the sky.

Colours to warm the rooms so they don't look and feel clinical.

We need to make sure clients have their favourite furniture photos, pictures.

Ensuring access:

There were a lot of concerns that suggest that at present client's basic access requirements are not being met. There were practical suggestions on how to make sure these are met in the new homes. Consideration needs to be given more widely to this.

Equipment such as chairs so they can get out of them easily.

Chairs not low and difficult to get out of.

Simple knobs and switches on machinery.

Large light windows and a lot of them. Most older people have less than perfect vision and good natural light is uplifting.

Better design to allow bedridden patients to interact with others. A solitary existence in a small room is a terrible way to pass one's final days, months and years.

Higher sitting room seats that clients can get out of easily. Dining room seats with wheels and locks.

Sitting room seats need to have wings on them so that clients have somewhere to put their heads when they are sleeping. The floors need to be wooden for easy hoisting but slip resistant so our clients don't slip.

These important points about ensuring good provision for people with dementia should also be taken fully on board by the Council:

It is of major concern to the Alzheimer's Society that the consultation document makes only a passing reference to dementia. Recent research demonstrates that over two thirds of residents of care homes will have some degree of dementia. This is likely to increase, given the demographic predictions and the fact that it is difficult to manage the risks attached to dementia in a community setting. Essentially, therefore, the service needs to be planned acknowledging the needs of dementia sufferers and their families, alongside responding to physical frailty. In the light of this we would urge greater emphasis in planning for dementia in terms of the environment and staffing. Much work has been done on the built environment and dementia in recent years and the redevelopment of these resources is a great opportunity to build sympathetic environments which will recognize the cognitive and perceptual needs of its users. We would urge that proper consideration be given to the research and the detailed proposals reflect best practice in design for dementia. The Alzheimer's Society is running a 'Putting Care Right' campaign which has been triggered by the evidence that people with dementia are generally very badly served in residential and nursing home environments. The redevelopment proposals are a great opportunity to address this situation in Cumbria.

Will the environments in the homes be dementia sensitive as this seems a golden opportunity to get things right from the start?

Perhaps we should visit other homes which are well known for being good for people with dementia?

We would like to make sure that the new homes take account of recent research into the kind of décor and design which can provide a calming effect for dementia patients and those with similar illnesses.

4. Making the Move successful – Keep communicating with all stakeholders:

This consultation showed that people valued being asked how to make the new homes as good as possible. The level of detail is testament to their commitment to achieving this goal. It suggests staff, residents, families and friends want to be involved. Indeed they state this explicitly in the answers to the final questions in the consultation. People were asked what could be done to reduce the stress caused by moving to new facilities:

Residents opinions sought on fitting out of 'their' own rooms at an early stage.

Communicate with residents and families in plenty of time so that problems can be resolved.

Letting the residents visit the new home before and after completion.

Give the residents ample time to digest any move.

Communication on a regular basis.

Good planning and preparation and leadership.

[K]eeping residents informed about the progress of the building programme.

Allow the residents to be involved in the process and look forward to it.

There needs to be constant ongoing communication between residents, carers, family and social care planners.

Questions need to be answered openly, support to explore fears made available. Open dialogue maintained. Good planning and involvement of residents, families, community groups essential.

Some respondents went further and advocate deeper more creative involvement:

We need to build innovation to prompt communities to design their health/social care sites. Ensure full engagements as Wanless

suggests is essential and compulsory within the next 5-10 years. Don't do half measures.

To enable success, staff residents and families should be enabled to own the project from its inception and encouraged to give input. A staff, family and resident committee/steering group could minimize disruption.

Section Three: Consultation with residents

If one of us were ill, we won't be far away. We will move to a different home. All the proposals are good and helpful.

I want my home to feel like a home, and if I am unwell I want to be in a hospital with patients not residents.

We need toys so that our grandchildren can play. We need outdoor toys, slides, swings and a sandpit.

Introduction

This central section reports the views, opinions and ideas of the older people receiving residential services through Cumbria Care. During March 2008 Shaping Our Lives asked three experienced and skilled service user consultants/researchers to talk with the residents about the plans Cumbria County Council has for their homes under the 'modernisation programme'.

Summary

Residents were broadly supportive of the Council's plans. Within this the following issues had particular significance:

Residents, including those on EMI units, like their home to 'feel homely'. For residents the key to this is:

- having friendly and helpful staff
- keeping the size of the home relatively small

To have a meaningful life residents, including those on EMI units, need the opportunities to enjoy the company of others. This can be fostered by having:

- an active activities and events programme
- a day centre on site
- spaces within the home for people to meet

For some residents of EMI units these are important:

- easy access to the garden and safe spaces to walk
- one to one attention from staff
- pets on the unit

Most residents want a meaningful community life.

This can be fostered by:

- Encouraging links with the community i.e. coffee mornings, church concerts, school plays.
- Siting the home in the community so residents can see 'the world going on'
- Having local homes so people remain in the community they have always been a part of

There is a lot of concern amongst residents about the location of the proposed new homes. This is particularly evident in Wigton but also present in the other homes. The concerns focus on:

- The homes being isolated and cut off from the community
- It being harder for visitors to 'pop in'
- Residents will no longer be able to use local amenities
- The new location will cause difficulties for staff

There is some opposition to change although most residents would welcome larger rooms, wider corridors and en suite facilities. Residents are concerned that if the homes got bigger they could lose their 'homely atmosphere'. This equally holds true for residents of EMI units.

'Dual registration' is, for most residents a good thing. However this is only true if the nursing section is quite separate and distinct from the residential side. People thought it would be depressing to be surrounded by ill patients and if they themselves were taken ill they felt it would be more appropriate to receive nursing care in a separate wing. Some said that by going to a separate nursing wing they would be able to keep their dignity. Residents also feared that the homely atmosphere for residential clients would be lost if the nursing and residential services were not provided as two distinct units.

For many residents the thought of moving is upsetting. To make it easier residents recommended a visit to the new home prior to the move. They also felt staff should reassure residents that they would be all moving together.

Residents had many ideas for an ideal home. These included accommodation for guests; accommodation for married couples; better use of outside space; meeting of access requirements and more information about their rights and entitlements. Most residents thought a shop in their home would be a very good idea.

It appears that many residents do not have information about domiciliary support services and some were unhappy that they had to move from their own homes.

How we carried this out

Ensuring Access

Shaping Our Lives is firmly committed to enabling all service users to contribute to any consultation process that will impact on their lives. In our experience the most meaningful consultations are those that use a variety of methods to allow service users to participate in the way that best suits them.

Using a semi structured interview schedule, these include face to face individual interviews and facilitated group discussions. The residents also had the opportunity to fill in the questionnaire as part of the public consultation if they wished.

Our experience has taught us that a facilitated group discussion is the most meaningful way for both the participants and for the people seeking their perceptions, thoughts and ideas. This is because, not only does facilitated discussion allow participants to 'kick an idea around'; but also a statement from one person can often lead a discussion in a new direction that those writing the schedule might not have anticipated. In addition people 'warm up' to a discussion, they can fire ideas off each other,

whether in agreement or disagreement and the entire process is far more meaningful and beneficial to all participants.

From past experience we have learnt that a group discussion should involve between four and ten people, however in this instance, we recognised that for access reasons four participants was optimum.

Cumbria County Council was equally committed to ensuring that residents had every opportunity to express their views and, if needed were supported to do so. To this end they commissioned the services of an independent advocacy organisation: Advocacy Experience. Advocacy caseworkers visited each home prior to the Shaping Our Lives consultation, and individually spoke to each resident. This provided the residents with an opportunity to share their views and ideas in advance of the consultation, including how they wanted to engage with the consultation process either through individual interviews or participation in group discussions. Advocacy Experience also offered residents the option of representing them if they were unable or unwilling to be involved in the consultation process. In addition they asked if people would like them to be present at the meeting. The reasons that people wanted the advocates to be present primarily fell into two groups:

- to prompt people if they forgot the issues they had raised with the advocate
- to help with communication problems

This proved very helpful to Shaping Our Lives' consultants. On arriving at each residential site the advocate and consultants met with a senior staff member to discuss which residents wanted to join a group discussion, who wanted to be interviewed on their own and where would be the most suitable place for the interviews to be carried out. It was important that the group discussions took place in a room that was private so that residents felt free to raise any concerns or worries and that the consultation was truly independent. Most residents

opting for a one to one discussion invited the researchers to their own rooms. In addition we were told of any changes we should be aware of. This included new residents and temporary residents who were staying for respite. Three people had died since the advocate had spoken to them.

We undertook this consultation using a semi-structured interview schedule. The questions were slightly different from the public consultation questionnaire because we wanted to specifically hear what the residents had to say as they already live in the homes.

Who we spoke to

We spoke to 55 residents of care homes run by Cumbria Care. In Wigton we spoke to 17 women and 6 men; In Millom we spoke to 4 women and 2 men; in Penrith to 2 women and 5 men; in Brampton 4 women and 1 man; in Alston 4 women and 1 man and in Keswick we spoke to 5 women and 4 men. Thus we spoke to 36 women and 19 men. In addition to this the consultants/researchers visited the EMI (Elderly Mentally Infirm) units for observatory purposes.

We spoke to 32 residents in 8 facilitated group discussions and we spoke to 23 individual residents. The length of the facilitated group discussion varied considerably with the longest being two hours and the shortest being 45 minutes. Individual discussions mostly lasted for about 30 minutes.

In the main this section follows the layout of the semi-structured interview schedule. Other issues that we report were generated by the comments and concerns of the residents whom we spoke to.

Shaping Our Lives assured all participants that anything they said to us would not be attributed to a specific individual. We said that everything we wrote would be anonymous. It is for this reason that names of residents have been changed and with the exception of Wigton nothing said is attributed to individual residents at specific sites. Wigton is

mentioned specifically because the residents are particularly concerned about the location of the proposed new home.

What people told us

1. What do you like about your home?

When we asked people to tell us what they liked about where they were living at the moment the majority of residents said they were content with where they were:

I find it very acceptable.

I couldn't say one wrong word.

It suits me very well thank you.

I have no more needs.

It's a good place to be, we have no complaints.

It's housing us, anyway.

[Living here] it suits me.

It's our second home.

I'd recommend it to anybody.

Most of the residents we spoke to found it quite difficult to articulate exactly what it was about their home they liked. As these residents of different homes try to explain:

I can't put a name to it....it's everyone and everything combined

It isn't easy I know to say what it is, but I've been to other homes and it's not there.

A large number of people would have agreed with the following residents:

It's homely here

It's homely

It's home from home

It's comfortable...like you feel like at home

It's a lovely atmosphere

We're a close family.

It is just 'home' to me.

I go on trips and I am glad to get home. I know where to go. Eighteen steps to the toilet and twelve steps to the dining room.

It's home from home here... they're all your friends

A few residents were more specific and tried to explain what they liked about where they now lived:

There are greenhouses, there's a seat out there that you can sit on, and round the back there's Japanese gardens...where the Alzheimer's is there is a garden and they can walk out and sit amongst it.

There are nice areas to sit, upstairs there are little links, and we have a nice day centre as well.

I think it's the freedom we have in here, you can go where you want.

I like the look of the place. Especially the carpets.

Some of the residents said that:

I like being looked after.

I like to be waited on.

It's a great thing not to prepare my own meals.

But in all the homes it was very clear that the one thing all the residents agreed on was that it was the staff that made the home seem homely:

It's really friendly.

All the girls are really good; they'll do anything for you.

The residents and staff are friendly.

I think its great, the staff come right away, there's no dillydallying, comfy beds, nice food, we really are looked after, much nicer than at home.

[...the staff] have been here for years, there's one girl been here over 25 years, she is one of the supervisors; she was one of the first that came.

Facilitator: So they must be happy here?

Oh yes. We have new ones that have come but they are all nice girls. I've been doing interviews for new staff.

I think it's the girls that make it myself.

The staff are very friendly

The manager here is very good at listening.

Facilitator: Do you like the staff and the other residents?

Oh yes.

Oh yes, everybody is very nice.

Equally most people seemed contented with the level of care and support they received:

I had a few rough nights but I ring the bell and they take care of things, they are thoughtful.

The staff are very helpful, both day and night.

Mind you, the staff are good: 'if you want anything, tell me and I'll bring it in next time I come', that's what I find the easiest.

We're well looked after.

I find TLC here and I couldn't wish for more.

Sometimes one's nicer than the other when they're helping you.

You can ask any of the lasses to get you something like, even a packet of cigarettes and they do.

If you need anything you can call.

Staff bring things in for people.

Nothing is too much trouble for them.

I must say this, the staff in all homes can't be all good, because my daughter-in-law is a Sister and she's worked in many homes and she wants to know if I'm all right when she rings and she says

to me, 'are you all right in there, cause if you're not, you're out!'

[The staff are] Very accommodating.

We heard very few negative comments about the staff. This exchange between two residents could be seen as a mild exception:

Some are good

They are all very good, but they have good days and bad days like any of us

The residents of one home had concerns about the shortage of staff which obviously impacted on the quality of the services the staff could deliver:

I could go out and have a coffee but now I'm blind I can't go on my own, I have to have someone to go with me.

I can't go out on my own now. Staff don't have the time.

Facilitator: Does this make it difficult to arrange to go out?

Yes, there is a staff shortage. I used to be a painter and paint landscapes.

There aren't enough staff. They are always very busy.

There used to be more [staff].

The place could have more nurses but they are short of staff.

2. A Meaningful Life

One of the important ways in which we make sense of our lives, how we get and maintain a sense of worth and value is through having a meaningful daily and community life. The residents in the homes we spoke to had varying degrees of success in giving meaning to their life in an institutional setting. In both the group discussions and the one to one interviews participants told us of the many ways in which they 'passed the time' and gave significance

to their lives. The researchers did not ask any direct questions about this but in all cases this information was volunteered. We feel it is very important to include what residents say in this Report as it provides crucial evidence of what residents want and need to feel pleasure and fulfilment in their everyday lives.

What people told us roughly separates into two sections. There is obviously slippage between the two and they are not mutually exclusive.

- Daily life
- Community life

Meaningful daily life within the home

An important aspect of the residential home for many of its residents is that it provides people with 'ready made' company. Some of the residents had experience of living on their own and of loneliness:

I think people like to communicate with others, we communicate with the staff, if we were on our own it would be extremely difficult. It could be very lonely. I sympathise with these elderly people who do live on their own, and only have someone come to see them for a couple of hours a day, I wouldn't like that.

Before I was living alone, now I like company.

Company is a great thing.

I don't live in my room; I go to the living in room. I like to be among people.

I like sitting where there is somebody, I mean I wouldn't sit in there [the lounge] if there wasn't anyone.

A few residents told us that they still experienced loneliness, whilst living in a residential home:

I like to chat at meal times but not everyone is sociable.

You see lots of people think it's a great idea for people to move into a home because they have someone to talk to, but the great problem with this, is the lack of communication in our society.

We are all strangers thrown together.

In one home we heard that having a day centre based in the residential home was good as it meant that residents got to meet more people:

You get to know people in the day centre.

I like talking to the day centre people.

For people using the day centre, it means they are familiar with the home before they move in, either on respite or more permanently:

I came once a week and then three times a week before I moved in, it helped me settle in.

I've only been here 3 weeks, I came for respite to start with.

I'm just here for respite. It was out of the blue... but I should be back this week, I want to go home.

I have been to the day centre now I am on respite. I know some people who live here which helps with respite. But I am looking forward to going home.

It is not surprising that many of the people we spoke to told us how important having meaningful relations with people were to them. Many spoke of how they had made new friends since moving into their homes, both with staff and with other residents.

Events and Activities

The majority of residents we spoke to told us of events and activities that the home organised for its residents.

There's a notice board where they put information. [If you can't read the board] they'll tell you what things are happening. We have a good activities girl. We have a man coming regular every month to have a singsong and we have a happy time. The girls have done a pantomime at Christmas for the last three years.

The organ man came, it was nice, but he wasn't on for long enough.

There's music, dominoes, egg dunking, bingo. It depends on what people like. It suits me alright.

There's a lounge, someone comes to entertain us.

We get entertainment at Christmas time, and a nice Christmas dinner. It was beautiful.

We had a man comes singing all the old songs, it was great, sometimes we play bingo.

The minister comes once a month

Other residents find different ways of living a meaningful life:

I go for the papers every morning, to the mini-market, 6 papers, I go every morning at 7 before anyone is up. I do a bit of sweeping up outside. It puts the time in.

You can get out, Clive goes to the market you see.

I listen to the wireless and they send a tape for the blind every week. It's very interesting; you get all the deaths and marriages, what's going on everywhere.

There's a garden you can sit out in. To get a bit of sun. It can get a bit stuffy. It's nice to get a bit of fresh air.

We feel that it is important to recognise that not all the residents felt that they were able to live a meaningful life. All three of the Shaping Our Lives' researchers reported that the residents we spoke to were all extremely pleased to be given the opportunity to talk to us. We were thanked copiously by many and we all felt that this was significant and perhaps reflected that residents opinions and ideas were not readily sought and/or that residents often felt rather bored. One woman told us:

I've never been bored in my life, but I'm bored.

Another said:

We don't have much to do here. Not really. People fall asleep in the lounge because they have nothing to interest them.

Meaningful community life

The people we spoke with told us how much they enjoyed watching people going about their everyday business. It made them feel that they were still part of the community which most of residents had always lived in. One home overlooked a school sports field and this provided much interest for the residents.

We see them over at the school, see them playing football and that.

Facilitator: Do you enjoy that?

Yes. You spend a lot of time looking out the window don't you Enid?

I like watching the football games and such and the children playing.

Facilitator: Some people said it was nice to have the playing field nearby...

Oh yes, you can see them playing out there.

Other residents just liked to see people in the 'outside world':

You see people going places.

Facilitator: Some people said they liked sitting outside more than in the garden. Can you tell me why that might be?

You can see more people out the front than you can the other side, you can see who is coming and going, you can see what's happening.

You see people you know going over to the bungalows occasionally

You saw someone you know Mary didn't you? Was it yesterday?

Yes I saw her from the window in my room. Crossing the road. I waved and she waved back.

I have a pleasant room; you can see people going past.

You can go out and sit on the terrace, this is what people tell me, if it's in the summer you can sit out

and see the people out and about, but I've only just got here, I'm going home soon.

For others sitting 'out the front' provides an opportunity to talk and communicate with other people:

It's company, you can stop them and have a chat if you want.

We like to sit out here [in the front] because you can see people coming and going, people from the bungalows come and have a word with us, and it doesn't matter who comes, they always come chatting.

I enjoy a good chat.

The residents who were supported, either by staff or friends and family, to go out for an evening or day recognised that this helped to, as this resident says, 'pass the time' in a positive way:

We go down the Star Club, they come for us and they fetch you back, there might be the Jubilee Singers or someone on the accordion, it passes the time'

Other residents agreed that leaving the home for a few hours a week was important:

I like to get out, just for a short while each week. Just to see what's going on.

There are things to go to, I go to the church next door, there's churches round about, coffee mornings, often have a brass band that comes to play at St Mary's.

We go on outings, we go for an ice-cream, or a lunch, or a spot of shopping.

My son takes me out every Sunday for lunch. I look forward to that.

A lady comes to take us out; we stop for a cup of coffee, go up to the lakes, which is good.

I can get out, I just tell them where I'm going, I just walk into town.

We had entertainment all through December. We went to see Helen Shapiro. There is entertainment for those of us who can go out and there is always something arranged for those who can't go so no-one misses out.

In one home the facilitator felt that the residents she spoke with did not want to talk about going out side. She wrote:

Residents appeared to avoid the question about going out, it was as if there was agreed resignation over being able to organise transport. There were one or two passing comments about arranging transport through the GP surgery for hospital appointments.

And one resident said:

If you are disabled it's hard to go out. We're short of staff and if we are out, we can't come back in but they are so busy. I miss going outside.

At a different home a resident said:

I would like to get out more. See things and talk to different people...but it is difficult.

In order to live a meaningful daily and community life it is very clear from what residents told us that people need to feel connected with those around them. It is important for residents to feel part of their local community. Whether this happens by locating a residential home in an already existing community setting where residents can watch people go about their daily business and interact with them, or whether it's a new build these issues are central to the well being of people in an institutional setting. These points were made forcibly by residents when we asked them about the councils modernisation programme.

3. The Plans for New Homes

Location

At Wigton the residents understood that plans already exist to move their residential home to the

site of the local community hospital. At present their home is situated in the centre of the town; the new home would be approximately 2 miles out of town, in the countryside. People travelling from the town by public transport would have to cross a busy dual carriageway.

The residents who we spoke to at Wigton were very vocal about these proposed plans. However, whilst Wigton is a specific site the residents of other homes equally voiced concern over homes being located in rural settings. We start with a discussion between two residents at Wigton and then we report what other Wigton residents had to say. We then move on to what residents from all 6 homes told us about the location of the proposed new homes:

Wigton residents

The residents of this home were very concerned about the proposed move.

It's too far away really, but I don't know where else you could get.

There would need to be a bus service.

They'd miss the shops. Those such as Frank go out to the shops, they can wander down the street.

If I may say this I'm, I think we'd be a lot better stopping here, I'd not be happy going up there.

They were talking about the auction site, but it's gone now. Tesco's have got it.

There's a garage with a bit of land behind it but I don't know if it would be big enough because you need a car park.

Facilitator: If the new home was built somewhere really central would people still be worried?

Not as much, no.

And this from other residents:

I like it here, because I have a scooter, and here I can go out whenever I want, down the street, into some of the shops.... its gets you out, where as if

you went out of the community where its all going on you would miss out on that

They've talked about moving up to the hospital, but none of us want to go up there, it's out of the way from everything, of all the amenities, from everything together.

I've been going to the doctor regular, I can just pop there. Where as if it were further they would have to bring me, and it's a lot of hassle.

Local people can walk here and visit the home a lot, and they don't need to have a car. To get up to another site they will have to have one.

People passing chat to us, whereas if you were somewhere else you wouldn't get that. I think you'd lose all that.

If you are out in the country, you've got beautiful scenery, but its not the be all and end all of everything, especially when you can't get about, when you are healthy you want to go for walks. When you are not, you can't.

I'd want there to be access to shops. When you can't get about, say if I was living out in the country, I'd only have the country to go in, where here it's like a country town so you have a bit of both.

I think this [Wigton] is the best place for the home.

I'm against moving away from the amenities maybe at the auction site or petrol station.

I think you should knock down this place and build it here again.

They say it's very difficult to get to, you've got to have a car, they say you have to use two buses to get there.

We heard very similar comments and concerns from residents of all the other homes. Residents like to be in a town where things are happening around them and where they feel part of a wider community.

Well the one advantage that Grizedale Croft has got is that it's on the flat. It's just next to the town centre, so the new site at the hospital would be quite a walk from the town centre, and I think that could be a bad thing for this place.

[Alston Hospital] It would put people further up the hill, it's further away from town. There are lots of people here who couldn't go shopping.

The point was to put it down on Church Road, on the flat; it's the only place it would work.

Some residents were anxious and worried about the plans:

Oh no, not up there on the hospital site.

Facilitator: Why do you say that?

Oh no, because its all up hill, there's bound to be somewhere in the town.

I couldn't walk that far now

There's quite a few people who say they don't want to go, they really don't.

Others appeared less concerned:

It doesn't matter to me where it is, as long as everybody's happy.

It makes it easier for people to call in and visit, because they might be doing their shopping at the same time and they are in town and so they think 'Oh I'll just go and see so-and-so.

It suits me, I don't live far away from here. I sometimes come in to use the day centre.

It's easily accessible from the station.

I would find it difficult if they decided to move it 20 miles away, it would affect the staff. The staff are already established, the majority of ladies are married with families, there would be a lot of pressure on them. Some of them have to start at 7 o'clock in the morning, so they would have to be up at 6, probably don't have breakfast, they haven't got time to, it adds a lot of pressure, bringing up a family, got to sort out their

husband's problems, its very difficult. So I think the location of these various places [the proposed sites] are wrong. Here is ideal, because it does allow the ladies who work here easy access.

I like to see the road, the people passing and so on...that's all part of what I like.

I like to walk outside into town. I have someone with me and I go quite often.

It's rather isolated where the hospital is, rather bad to get to.

You're cut off by the by pass, it's putting a lot of people off, like.

If it was up there you would miss all the comings and goings, you wouldn't have that up there, and, you know, that's your life. I've always had people around me and I'd hate to be stuck where there weren't people.

It'd be good to have a new home in a town so you felt you was a part of what was going on and you could see it all.

Amenities in the home

When we asked the residents if there was anything they would like to change in their home or would like to see in a new home all three of the researchers were struck by the low level of expectation from the residents. These responses were typical:

Bigger bathrooms wouldn't make any difference. I can't wash myself, can't dress myself, well only to a certain extent, so really I'm happy to take what they offer.

If people are unhappy, they just accept it.

My room's nice enough, I mean it's small, smallish, that doesn't matter, I mean you're only in it for so long anyway.

What's the matter with this one? I think it's wonderful, spend the money on something else!

She's right there, a lot will say that.

What's wrong with Inglewood?

We've been getting new furniture which is lovely.

I'm a bit 50:50. Is it worth spending all that money?

My room is ample, I have a toilet and a shower... own bathroom not necessary.

I'm very near to a toilet. It's just across the way, I tend to forget my commode.

It's O.K. here. Most of us aren't here that long. Doesn't matter much to me.

Other residents however did have stronger views. In particular these related to:

- Room size
- En suite facilities
- Corridors and doors
- Food

Room size

The majority of the residents in all of the homes felt a larger room would be good

The rooms would be better bigger.

I think the rooms could be a bit bigger.

I brought my own bed and chair, but with the chair, there's not much room to move.

I think it would be better with bigger rooms and more en-suite facilities, so you can be self contained like a one bed roomed flat sort of thing.

The bedrooms are a bit small; they could do with being a bit bigger.

The rooms are for midgets!

Mine is a midget, its minute it's very very small.

You could have a table and chairs. But with the numbers of visitors I have it wouldn't be worth it!

I want a bigger room and my own toilet.

Yes, a shade bigger would be good.

This view was not universal:

Yes, but as you say if the rooms were a bit bigger, you'd have more room to move about, but they are adequate

I don't know if I agree with what Ted says about having a bigger room, I don't think we need bigger rooms, the bigger the room the more it takes to look after them, its got to be cleaned out. They are big enough to entertain two and three visitors.

It's alright with me.

[Room size] suits me

We were told on more than one occasion that there were no 'private places'. This seems to centre on having privacy when talking to ones visitors and needs to be considered along with the size of residents' rooms.

I'd like some space to have visitors

I'd like a bigger room so I can have a private talk with my visitors.

I don't like having to take visitors to the lounge where other people might be.

En suite facilities

Most residents thought that having en-suite facilities would be a good thing:

I could do with my own toilet.

I think everyone should have one [an en-suite].

My dream is for me to have my own loo.

I would like my own toilet and shower. It would give you more privacy.

I have bowel and kidney trouble and I could do with more privacy. Some residents take a long time in the toilet, they can't help it. I take a long time and if I can't wait I keep a bucket in my room. It's not nice.'

Will we have our own toilets and hoists? It is difficult as I can't hurry. I am slow to walk or do anything.

One resident explained that it didn't matter to her:

I'm alright I've got a toilet just opposite me.

Other people didn't express a view either for or against having such facilities:

There are 40 rooms and just 4 en-suites.

There's no sanitation in the room

These new homes, you'll have your own shower, here you go for your bath once a week

Doesn't bother me either way. I suppose it is a bit of a waste of money. Who is going to pay for it all?

Perhaps this resident explains why some other residents are not concerned about having en suite facilities:

You get used to it [not having your own bathroom] you get institutionalised.

Three different residents were not in favour of en suite facilities.

I'm alright as I am, I mean there are a lot of people who need help to be bathed so why would you need so many?

I don't agree with having individual bathrooms, I think a bathroom has got to be shared by other people, on different days or times.

That's alright (having en suite) if you can use the bathroom yourself, but if you've got someone coming along to do it, there won't be any use.

It later transpired that all three residents needed assistance and were very worried that having en suite would mean that they did not get the support they needed. This highlights the importance of carefully thought out, accessible information about the modernisation programme that needs to be readily available to all residents.

Corridors and doors

Many of the existing homes have heavy fire doors and narrow corridors. All the residents viewed these as a barrier to easy movement within the home.

Wider corridors would be superb, I use a Zimmer and I can't get past people ok.

The corridors are very narrow, so if there are a few of us we would struggle to get down, so wider corridors would be better.

If I met anyone on my scooter out there, I would have to back out.

...Its difficult getting out on my scooter from the staff room.

Some of the doors are very hard.

If somebody comes I have to go to the side to let them pass.

Corridors could be a bit wider.

Wheelchairs get stuck in the corridors and a member of staff has to come and help people reverse. They should have to get a drivers license!

We need those electric doors that open for us.

The doors are very awkward, some shops have a button you can press, and they open at your command, that's what you need.

Food

Although no questions were asked about the food in the residential homes, we heard a lot about the food. Indeed all the researchers commented on the importance people placed on being in the right place at the right time to ensure they did not miss their mid morning cup of coffee, or afternoon tea. It is well documented that in an institutionalised routine day these breaks take on more significance than they might otherwise.

Although some residents were happy with the food:

Very good, no complaints about food.

Oh, the food, it couldn't be better, really.

Lovely food. I don't know how they do it all.

Other residents are less happy. This resident echoes what many told us:

When I first came in here, we used to have our food cooked here, and now it comes from the kitchen upstairs...so sometimes its damn cold when you get it. Other days they say they'll send it down at a certain time, and no one is there to collect it so it just sits there getting cold. Sometimes I would like a nice hot dinner.

The food could be improved. There's no menus but they can't please everyone.

Sometimes the food is alright and sometimes there is a choice.

The food could be better. I'd like steak and kidney pie.

Every meal isn't perfect but that's the same as home.

It's better than hospital food, hospital food is terrible, the food is made here, that is the main thing.

Food is obviously very important to some of the residents. Thus we feel that when the new homes are developed residents wishes around choice and locally prepared food are taken on board.

4. Dual Registration

When people were first asked about their home becoming 'dual registration' most residents looked upon it favourably. This was said in a group discussion and the other members of the group all agreed:

I think it would be a good idea. You come into a home like this and then if you are ill, too ill to help yourself, you'd have to go into a nursing home, so I think having the two combined is a good idea.

Other residents also agreed:

That's a good idea.

I think its necessary myself.

It serves two purposes then.

More nursing staff, more individual help for those who need it.

Well, if it improves their lives and gives them a better experience, let them have it, as far as I'm concerned, let them have it.

I think that would be alright.

That's good, I think.

Spot on, that's my opinion.

Everybody would want to go to the new place

I wouldn't mind moving, as long as it in was Alston

I think it would be better, I mean they fetch them to the hospital anyway, so it wouldn't be no different would it.

It is vital to acknowledge, however, that whilst there was a lot of enthusiasm for a dual registration home, residents also had a lot of concerns. As we have already stated residents value the 'homely' quality of where they live and would not like their homes to lose this.

Size of home

The majority of the residents expressed concern if dual registration meant that their home would get larger than it is at the moment:

Some people are worried that bringing the two [residential and nursing] homes together would make the place much bigger.

I prefer the smaller homes, you are like one little family, its like being at home with your family.

I've been in here six years, and a lot of those [people] upstairs I don't know yet. To go upstairs you have to go up in the lift, which I hate.

Whatever is going on the girls take you up there. All the children come in from schools at Christmas to sing carols; the girls will bring you up. You're not isolated at all, but it's just not easy to get up there. So there are still people up there who I don't know.

It would alter the face of it.

I think it is necessary but it would change the atmosphere, it would be bound to be different if it was bigger.

The smaller it is, the closer knit it is.

I don't think it should be any bigger.

Facilitator: Why's that?

It's big enough to contend with.

More than 40 people would be too big.

It would be too big if there were more people.

Only one resident expressed the view that a larger home would be beneficial:

We'd be better with a bigger home. I don't know, it's nice in here but I would rather have it bigger. There would be more people to speak to.

Two homes: one site

The three researchers all noted that, without exception, residents of the homes all assumed that if or when dual registration took place this would mean that the homes would be clearly divided and separated into two quite distinct and self contained areas: residential and nursing.

I think they should be separate. I think that would be better, much better. They could not be all mingled together.

To me you are getting everything here already. You've got the doctors and nurses coming in everyday, you can't fault that. I'm one of the lucky ones that can get out and it only takes me a few minutes to go to the clinic, but if I couldn't go the nurses are in and out every day. There are two

or three doctors. You could just call. You get the quality in that side of it.

I think it would be alright separate just not mixed up together.

I think it should be separate.

I don't think it suits everyone to be together like that. I think it's more private like that [separate].

It's not everyone who likes a nurse being around.

That's what I would like to see yes, to be separated. If someone was taken very ill, they could be taken to another part of the building.

I can't see it being workable [not being separated]. I find it difficult to put an estimate on how that would work; it would make it bigger and bigger and bigger. I like the size of this one, we all know each other.

I think dual registration would be good idea.

Facilitator: Other people have said they would be concerned about living next to very ill patients.

No, I'm not very concerned, as long as that part of the hospital is separate, for everybody's benefit.

Facilitator (to group): You all seem to be telling me that you think that a 'dual registered' home, nursing and residential, is a good idea.

Yes

Facilitator: Do you think there would be any disadvantages to you living in that sort of home?

I see it as one big building but nursing care separate.

Yes, I just think that's necessary, surely?

Nursing would have to be separate. You wouldn't want it any other way. Oh No.

It should be two different wings of the same building.

I would want to be separate if I was poorly.

I think you'd be better with a nursing home attached to the new home

I think it's a good enough idea as long as there are separate wings, that's my opinion.

It was very clear that people wanted to draw a clear line between the residential home and that part of it that would be the nursing home. When asked why this was peoples answers tended to fall into one of two groups:

- To be surrounded by ill people would have a negative effect on residents
- If people were not feeling well themselves they would rather be away from other residents and be in a more hospitalised situation.

This is what residents said:

I wouldn't like to see people who were very ill in the room next to me.

I've always had a laugh here, there have always been nice people, there are 8 of us here in larches, I've never been miserable. But I spent 12 months in the orthopaedic hospital, I know how bad it was then, because there were so many people ill around you, and it makes you feel ill, you just feel depressed.

I know what its like, I've had people ill in this bed and people desperately ill in this bed, and it's not very nice, I mean it happens to us all at some time, but it's hard to take.

If it was a nursing home people might think you are crackers.

It would be depressing. If you were in an environment where people were ill all the time it would get to you

You would have people in bed; it would have to be a big place, a miniature hospital. You are talking about bedded patients. I think that would be extremely difficult to introduce

Facilitator: – So you wouldn't want your home to become a nursing home?

No, certainly not. It's more private isn't it? It doesn't suit everyone to see that does it, it can upset people.

Dignity and Privacy

There was concern amongst some of the residents that if they became ill and were not moved to a separate nursing area it might cause embarrassment for both them and their fellow residents:

There are people who can't use the toilet and that, and that's just wrong. I want to keep my dignity

I don't want to be wheeled around on a trolley or something, not in front of people who you know.

You want to keep yourself private like.

In hospital it is different because you are all in the same boat. Which is not the same as being here.

Hospital Rules

Equally residents expressed concern that if the two homes were run as one, then it followed that the nursing home regulations would be imposed on the residential home and on the residents. This worried residents:

If it is nursing care the whole feel of the place would be more like a hospital. You might not be able to have carpets, different standards that would make it not feel like a home.

...[the home] might have a cold look.

It might feel like a hospital.

The smoking room would have to go.

Would we be allowed to keep our cat?

It could turn into a mini hospital.

You would always be under a microscope.

You could lose individuality.

I wouldn't like that.

The advocate reported from one home that:

If their home becomes registered as both a nursing and a residential home it was suggested by some residents that there would be more segregation between men and women. In this home at the moment the residents mix quite freely, and some people we spoke to were concerned at what impact this would have on their home.

In general there is a lot of confusion, uncertainty and misunderstanding about what it will mean for residents if their home becomes 'dual registered'. Most of the people we spoke to had little understanding of what this means in practice and the implications for the home. Residents feel that they have not got a clear picture of what the home might look like. For example, would the residential quarters be separate from the nursing quarters or would it be mixed. Residents would welcome more easily accessible information on this and on how it might work.

5. The Move

The researchers asked the following question:

If the proposals go ahead, existing residents would move into the new facilities, do you have any concern over the move?

For most of the residents the thought of having to move was very upsetting and most people did not relish the idea:

It would be a bit of an upset.

I don't know, I really don't know, it would be an upheaval for anyone who was a resident here.

You get used to doing certain things, in a certain place.

I wouldn't go out of Wigton

I hope I don't have to, I don't want to move.

I don't want to move. We are just going to be told what we have to do. We are shoved here, shoved there...do this do that. I don't like it [the thought of moving]..

There were a few residents who were not disturbed by the thought of a move:

You get used to things, people can get set in their ways, I believe in moving with the times.

Well, it could be better, I'm sure they'll do their best to make it better. I don't really mind. I'll just go with the flow.

It's fine as I am at the moment.... I didn't have concerns when I came here, I had to sell my house to come here, I had to come here, I couldn't cope on my own. I just accepted it. If we have to move we will all just accept it.

I think it would be different to here, and I think it would be better. There's only one disadvantage to it, the only problem is it being out of town. Good if it isn't so far out of town. If it was central it would be better

Others had suggestions of how to make the move smoother and less worrying for residents:

I'd think they'd make things as easy as they could.

Facilitator: What could they do to make things easier?

Reassuring us that it's going to be ok.

No, I wouldn't mind as long as I was among the people I knew, that's the important thing.

It would be alright if we all went together, residents and staff.

This suggestion received a lot of support from others in the group:

I would like to have a look at it [the new home] before I moved in, if I didn't like it I wouldn't move in.

In a different group a similar comment also received support from other residents:

I think if they took some of us on a trip to see the new home, we could tell others what it was like and the fear of the unknown might go.

These residents tried to explain how other residents were feeling:

At my age, and there's people older here, they don't like change, they're frightened of change.

Facilitator: Are you?

Not really, but there's quite a few are, because when that chap came to give us a talk...well, all they could say after he'd gone was 'they're going to take us out of here'. Some was saying 'we're going to be turned upside down' – the biggest fear was moving.

Facilitator: what do you think it was about that that worried people, just change?

Yes. The biggest thing they said after he'd gone was 'Oh I don't want to go, I don't want to go'. They don't like change. They didn't understand they'd be comfier, like, they were panicking. They're frightened of moving.

A lot that's in here like this place, now, as they are. They don't want change.

Facilitator: Do you think it makes people feel better knowing that the staff would be moving with them, because the staff seem to be very important to people?

Yes, they'd be going as well and that will satisfy a lot of people.

We cannot underestimate the general anxiety and worry that the majority of the residents we spoke to, feel about a move to a different site. Residents made helpful suggestions about how some of the fears might be allayed. These include visiting the home before the move, reassuring residents that residents and staff will be moving together, and ensuring there is ample accessible information made available to residents about the move.

6. The Perfect home

We asked residents if there was anything that they would like their home to offer them that it does not do at the moment. We asked them if money were no object what would your ideal home look like.

Guest Rooms

One of the first things that people talked about in two of the small group discussions was making a room available where guests could stay:

There is no where for visitors to stay. My daughter has a long journey to make.

Oh no there isn't a place to stay.

Facilitator: Would that be a good thing, a guest room?"

Yes. Yes it would

My relatives live in Sheffield, and they've nowhere to stay so that would be good to have.

Yes I think it would [be good to have a guest room].

In a different group not everyone agreed:

Could we have a room where visitors could come and stay?

We'd all like family members to stay overnight.

If a person comes to visit me, you couldn't have provision for someone to stay, that's completely out of the question. People come to see you and you talk...but as for staying. No.

No guest room and I'm not bothered.

Accommodation for couples

We then asked residents if they had or would like to have facilities for couples who live in the home. With the exception of one resident every one thought this would be a good idea. One person had had the experience of moving into the residential home with their spouse but they had had to have separate rooms:

When I first came in I came with the wife, we had separate rooms.

Facilitator: Would you have liked to have been together?

Yes it could have been better.

Other residents thought it would be good to have accommodation suitable for couples:

Here there isn't a room that would hold two people. But it would be sensible. Oh yes. I know of a place, the two front rooms weren't furnished, and the couple could come and bring their own furniture.

I think there's a bit of a shortage [of double rooms] in most homes. A friend was in a nursing home in Silloth, and the husband and her had to have separate rooms. There was some one here, Glen and his wife they had to have separate rooms.

This resident was quite upset when we discussed the possibility of catering for married couples:

[The home] It couldn't have a husband and wife, they would come and reside here all the time, its not what this organisation is all about, its about retired people and sick people, you couldn't have a husband and wife set up here, it would be all wrong, I don't think it would work.

He went on to say:

They'd have to have single rooms wouldn't they?

Some residents made some very specific requests.

I wish I had a kettle

We need a desk for our enquiries.

An arena, a sports ground for kids.

Young people to meet up with us

I'd like a swimming pool!

These also included three comments from residents in three different homes, about the lighting:

The lighting's not so good here; it's difficult with my eyes.

Cumbria County Council need to make sure that the lighting is good to make it easier for people with visual impairments.

I would like some bright lights. I find it always dark in the lounge and in the corridors. It makes it difficult.

We were told that none of the homes had parking space available for motorised mobility scooters.

I had a scooter at home, but I couldn't bring it here, cause one lady has one. They don't have the proper facilities to keep it in, I've just left it in my son-in-laws garage, he's going to sell it for me. I used to like going up the street, two or three times a week. It would be handy here so I could go up the shops. I have a friend up north whose home has facilities for scooters.

There isn't any accommodation for people on scooters and things...I've stuck mine in a garage over there, but I could use it up town

Parking for scooters please.

I would like to have had the chance to go out on a scooter. But we have nowhere to store them.

One resident thought mobility scooters were not a good idea:

I'm totally against anything like that [mobility scooters]. Quite frankly the people who are driving those things are not fit, they shouldn't be seen on the roads.

There were quite a few comments concerning outside spaces:

The garden has gone to wrack; it would be nice to have it nice.

We could get more seating [for the garden].

I think it would be better to have a garden where you can sit out, there isn't much garden here.

It would be nice to have good flowers in the garden.

One resident said that he wanted the bathroom designed so he could easily have somewhere to soak his feet, for as he puts it: 'it makes you feel altogether different'.

There were a few comments that raise issues about the standard of personal care that some of the residents were receiving:

The washing done properly, and know you will be looked after and to be well bathed.

I would like a home where I can have a proper bath, take all the time I want and not be rushed all the time.

I would like to be perfectly clean.

It should be noted that this last comment is not a reflection of any lack of personal care received by the resident as she later went on to explain that she was concerned that the current standards should be maintained.

Several residents discussed the possibility of having a conservatory:

A conservatory would be nice

I think that's a splendid idea, it could throw it down from the skies and it wouldn't matter.

I think that's a good idea, glass all round.

What a good idea.

We need a conservatory so we can enjoy the garden. There needs to somewhere covered so we can see out and keep dry. If we go out, and can't get back in, we can't summons help for the toilet. It makes it hard to go out but we could have a little covered space outside the front so we could see people going by.

I'd have a conservatory and a little shop.

The majority of the residents who we spoke with said that a shop in the home would be very useful and would give them a feeling of independence:

A shop would be good, to buy sweets, cakes or anything that you like.

Otherwise you have to get someone to bring it in for you.

I wanted to buy Easter eggs but I had to ask my daughter in law to buy them.

I need to be accompanied to go to the shops. So a shop here...

I would like a shop, I'd love a shop.

A little shop selling odds and ends.

A Shop? What a good idea, if they're going to build a new place they could do it.

Yes, that's a good idea. We do have a lady that comes round and she's quite useful, but you don't always see her. It would be good if it was there all the time.

Oh I think we should have a shop.

Whilst the majority of the residents we spoke to clearly thought that a shop located in the home was an excellent idea, a couple of people did not:

No, no shops. A shop is used for all types of people, children, a shop wouldn't be economical, if you were trying to sell anything to anyone.

No you don't need that [a shop]. You've not got far to go down the road to the shops.

Other residents had different ideas about what they thought a perfect home would offer its residents. These two residents want access to library services:

What about a cinema club?

Oh yes and a library I'd like that.

They could get a library van to call each week.

Yes what a good idea.

This woman explains why she can't go to any of the courses that are run in the evenings:

In Wigton there are night classes, like pottery, sewing and stuff...but unfortunately all these classes are at night, and old people don't like to come out at night, so it would be nice if they could offer them in the afternoon.

This was a very specific request:

Tell them we would like a big clock and calendar on the wall because none of us knows what day and time it is!

Many residents thought there was a need for a games room:

A games room where we could play board games.

We could have a games room, bowls, tennis, library, sewing and reading room, hairdresser.

Lack of accessible transport was a barrier for the residents and denied them access to the rest of the community. Many residents talked about this:

A bus service for a few hours a day is what I would like.

We don't get out but some kind of van or vehicle to get on, such as a bus.

We could do with a bus and a driver.

Other residents discussed the need for a prayer room:

Some would say a little chapel.

That would be lovely.

But we have one here and nobody goes.

Yes, the spiritual side is important

I go to the local church, so no I don't particularly want a chapel or prayer room.

This group of three women wanted the council to give them more information about their rights and entitlements:

In Carlisle you can get a scooter [shopmobility]. But in other places there is nothing for disabled people. In Wigton there are not many shops you can get in with a scooter. I think the council should do more to help people who need it. People need more information about how to go about getting to places. For example I have a disabled key for the toilet....a lot of people don't know about that...

People should be telling you. I think there should be more information for anyone who is disabled. People don't know where to start'

There are organisations, like Age Concern, but they aren't always there, I don't know where you would go.

Everything is printed on paper and not everyone can read.

It would be very useful if the home or the Council gave us more information about what we can have. About our rights and entitlements. We don't know how to find out.

We could have lessons on the internet and then we could find things.

It is very noticeable that even when the residents were encouraged to dream about 'the perfect home' not one respondent suggested anything that was out of the ordinary or prohibitively expensive. Indeed many of the residents showed a deep concern with how much the modernisation programme was going to cost and who was going to foot the bill.

Most of the resident's suggestions for a 'perfect home' are things that the younger 'general population' take for granted: transport; access to libraries, education and churches; being able to shop, visit the hair-dressers and offer accommodation to visiting friends and relations. People want their basic access requirements met: adequate lighting for visually impaired residents; mobility scooters for those with ambulatory impairments and good support with personal care. Residents want information about their rights, their choices and their futures.

7. Support to stay in your own home

Discussing with residents why they chose to move into a residential home rather than opting for services to support people to stay in their own homes is not only a very personal and private decision but has the potential to be distressing for

residents. Thus we did not feel it appropriate to raise this issue. However we report here the comments made to us on this topic.

One can sort of cope in our present mode of living, I would find it extremely difficult to exist if I had to cope on my own

I'd like my old house back.

If I won the lottery I'd like to go back home to my bungalow.

If you want the truth I wouldn't be in here, knowing what I know now.

At home I could come and go as I wanted, cook what I wanted, buy what I wanted.

This place drives me barmy, I'm used to a four bed farm house. I'm used to a lot of space.

They say my house has got too many stairs...it's in the middle of nowhere. It's a location problem. I am typical of Alston Moor, houses are scattered everywhere and wherever you go in Cumbria it's the same. People come here because it's quiet, but then how you provide services I don't know. The government aren't willing to spend.

My one dream is to be back in my own home.

The following comments are all made by people who are temporary residents of the residential homes. They are all recipients of 'respite care'.

I like being on respite. I can't cope at home. I'm anxious being at home. There are social workers if I need to speak to someone. I need help as I'm not well.

I don't want to stay here. I'm not ready yet. I want to go home. I've always looked after myself. I'm not giving in that easy, but I do want someone looking in.

Facilitator: Do you have that when you're at home?
Not really.

I've been here a month and I must admit I'm getting ready to go home, but that's not Inglewood to blame.

Facilitator: What are you looking forward to about going home?

I love my little bungalow, it's my home and I want to stay independent as long as I can.

I'd rather stay at home and have care at home than move out to Carlisle or wherever. Wigton's close knit, there's people I know here.

The residents that spoke to us about wanting to live in their own homes rather than in a residential setting did not seem to be aware of domiciliary support services. Whilst some of the residents said that they would not like to be at home as they would feel isolated and lonely, there were a sizable number of residents who apparently had little awareness of support services and options that might have enabled them to continue living in their own homes.

EMI Units - Observations

Two of the three Shaping Our Lives consultants visited four separate EMI units at four different homes. They did not attempt to use the interview schedule as they felt it would not be appropriate for this group of service users.

However, they both talked to many of the residents on the units, in all cases on a one to one basis. They also spent time sitting with the residents in lounge areas and observing.

These are the main issues that the consultants felt need to be taken into account when planning the new homes for residents of the EMI units:

Residents appeared to like company and someone paying them attention. One consultant wrote:

They really seemed to come alive when they were talking with us

And another wrote:

The residents appeared to enjoy talking to us and some were quite chatty and smiley.

They both commented on the fact that the staff did not seem to have much time to chat with the residents.

One staff member commented that she thought it was inappropriate that there were only two members of staff present at the home throughout the night shift and that this meant that residents of the EMI unit could go for two hours before being checked. She felt this could result in distress for some of the residents if they became disoriented during the night.

Residents of the EMI units appeared to enjoy mixing with other residents of the home. One had been at a focus group we ran on another unit. She said she sometimes visited her cousin who lived on that unit. One resident liked to smoke. Staff at that home said that they took her to the home's smoking room and she also liked to talk to other residents there.

The consultants observed that in some of the homes space in which to wander was important for the residents. Not all the units seemed to allow for this.

One unit had a cat wandering about. One resident in particular seemed to benefit from this; the cat sat on his knee and he said that he liked to stroke it. He said that it sometimes sat on other peoples knees.

Some residents said they liked the garden. The consultants reported that there was no obvious entrance to the garden from most of the units.

In one of the Units members of staff made the point that in the new homes, the design of the bathrooms needed to be considered carefully. This was not just for the residents but to facilitate staff caring for them. They suggested that the bathrooms needed to be large enough to allow for two members of staff and a resident to all be in the room together. They also suggested the availability of bathing pools and massage.

People generally seemed to be less contented than the people we had spoken to on the other units. When we asked them if they liked the home, they tended to respond with phrases like “it’s alright” and “it’ll do”.

The consultants observed that the residents in the units could benefit from more to do, particularly with other people, during the day. It was noted that some units had either a television on or music playing but that it was not geared, or particularly suitable for the resident’s generation.

The atmosphere of all the units that we visited was homely. They were domestic in scale and décor and the residents all seemed comfortable, relaxed and at ease.

