



Social Services Improvement Agency

# Hearing the voices of older people in Wales: what helps and hinders us as we age?

## Research report

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# Contents

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<b>Acknowledgements</b> .....	4
<b>Foreword</b> .....	5
<b>1. Introduction</b> .....	8
1.1 <b>The questions we set out to answer</b> .....	8
1.2. <b>The 'anatomy of resilience' model</b> .....	9
1.3. <b>Understanding the crisis triggers</b> .....	10
1.4. <b>Where we went, who we spoke to</b> .....	11
1.5. <b>A note on language</b> .....	13
<b>Chapter 2. What matters most to older people and their carers?</b> .....	14
2.1. <b>Being independent</b> .....	14
2.2. <b>Feeling good about yourself:</b> .....	17
2.3. <b>Being connected to others</b> .....	18
2.4. <b>Staying active</b> .....	19
2.5. <b>Being well</b> .....	20
<b>Chapter 3. Relationships</b> .....	22
3.1. <b>Partners: bereavement, loss and new beginnings</b> .....	22
3.2. <b>Relationships with children</b> .....	23
3.3. <b>Becoming a 'carer'</b> .....	25
3.4. <b>What makes caring easier?</b> .....	29
3.5. <b>The role of friends</b> .....	31
<b>Chapter 4. What helps or hinders older people in achieving well-being?</b> 33	
4.1. <b>Transport</b> .....	33
4.2. <b>Home environment</b> .....	35
4.3. <b>Neighbourhood</b> .....	39
4.4. <b>Money</b> .....	43
4.5. <b>Information Technology (IT)</b> .....	45
4.6. <b>Black and Minority Ethnic Older People</b> .....	47
<b>Chapter 5. Services: Perceptions and Journeys</b> .....	51
5.1. <b>Perceptions and experiences of Social Services</b> .....	51
5.2. <b>Perceptions and experiences of the National Health Service</b> .....	57
5.3. <b>Perceptions and experiences of the voluntary sector</b> .....	61
5.4. <b>Access to information and advice</b> .....	64

**Chapter 6. What is the learning for a whole system approach to 'prevention'?** 66

**6.1. Introduction** .....66

**6.2. Context**.....66

**6.3. Prevention and independence– the evidence of what this means to older people and carers**.....68

**6.4. What are the implications for Government, policy makers, practitioners and other organisations that seek to assist older citizens?** .....70

**6.6. What does change mean in practice? What are the levers for change?** 72

**Appendix 1: Methodology** .....81

**Appendix 2: Demographics of our sample** .....84

**References** .....92

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## Foreword

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### **Sarah Rochira - Older People's Commissioner for Wales**

There has, in recent years, been a significant and welcome shift in focus towards a more preventative approach across our health and social care services – supporting people to remain healthy and independent, rather than simply responding when a crisis occurs – essential to ensure that older people in Wales can access the services and support that they want and need.

A more preventative approach to delivering social care services underpins the Social Services and Wellbeing (Wales) Act, legislation that has the potential to transform social care in Wales and make a real difference to the lives of older people when it comes into force in April 2016.

But producing legislation is, of course, only half of the story. The real challenge now is to ensure that the intentions to deliver positive change that run through the Act are translated into real action by our public services and, most importantly, that this action delivers what older people actually want, rather than what a service assumes they want.

Public services will only get things right for older people when they listen to their voices and respond accordingly. This may sound like a very simple thing to do, but often this vital step is overlooked, resulting in 'one-size-fits-all' services, as opposed to person-centred services designed to respond to an individual's needs.

That is why I was so pleased to see the voices of older people included throughout this report: their hopes and fears, experiences and wisdom offer essential guidance on the way services need to adapt to meet people's changing needs, support their independence and allow them to continue to participate in their communities.

By not only highlighting the barriers that older people face in getting the services and support they need, but also making clear what older people say works well, this report will be a highly useful tool to inform the development of innovative, person-centred services that will give older people the choice and control over their lives that the Social Services and Wellbeing (Wales) Act sets out to deliver.

But more than that, the methodology that underpins the report, which has the voices of older people at its heart, provides both a starting point and a potential model for the population needs assessments that will soon be undertaken to map out people's social care needs across Wales.

It is clear that there will be challenges ahead and that significant cultural and organisational change will be required to ensure that social care in Wales will meet the needs of older people. However, by using older people's voices effectively to underpin the design, development and delivery of social services, Wales has a real opportunity to get things right for older people, both now and in the future.

### **Rhian Huws Williams - Chief Executive, Care Council for Wales**

The Care Council for Wales warmly welcomes the publication of this report. It is vitally important that we hear and base care and support on the views of older people and what will help them stay independent.

The Care Council is committed to developing a care workforce which acts on the basis of an equal relationship between those receiving and providing care and support. We emphasise this through every aspect of a care professional's career. From induction to qualifications, to continuous learning and development, we emphasise the importance of the individual's voice and control, enabling independence and strengths based approaches.

This is exemplified by the importance placed on these approaches in the new and updated Code of Professional Practice for Social Care, to which all care workers must adhere. The Code states, for example, that all social care workers must "support individuals to maximise their decision making and control over their lives."

This timely report coincides with the Social Services and Well-being (Wales) Act coming into force, which aims to place prevention and early intervention at the heart of provision. The Care Council has developed extensive training materials to support this improvement, which emphasise throughout the central message of this report that what matters to citizens and communities matters to social care professionals too.

### **Sally Ellis - Former Director of Social Services in Denbighshire and Chair of Strategic Improvement Steering Group, Older person ageing in Wales**

"This reports provides an invaluable insight into the things that support or get in the way of our independence and wellbeing as we age. Based on an extensive programme of interviews with older people in Wales, as well as a literature review scanning experience elsewhere, it will be of great practical use to local authorities and their partners as they plan and implement prevention and early Intervention approaches and develop Population Needs Assessments and Information, Advice and Assistance services. Essential reading."

## **Graeme Francis - Head of Policy and Public Affairs, Age Cymru**

We welcome this research, which we hope will make a valuable contribution to the development of future support for older people. The conclusions match many of the conversations Age Cymru hold and the areas older people tell us are important to them. The use of 'resilience' as a concept is becoming more widespread and provides a valuable lens through which to consider the combination of factors which can influence a person's well-being and independence.

This is a crucial time for developing appropriate forms of support for older people. The implementation of the Social Services and Well-being (Wales) Act 2015 is an important milestone for social services, but it comes in a challenging financial environment. Anything that can aid the understanding of the outcomes that matter most to older people, and the barriers that some people face, should be extremely valuable to those who design, manage and deliver services.

# 1. Introduction

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*"I'm completely content with life. All of it has prepared me for what is coming ahead."*

*"I'm only just managing [financially] – that's because I don't go out ... I don't have holidays; I've got no social life – is there anything for old people like me"*

*"We are the people who do not shout".*

## 1.1 The questions we set out to answer

- What are the outcomes that matter most to older people in relation to their personal well-being?
- What are the real and everyday barriers that most prevent older people attaining these outcomes?
- Which roles do and might statutory and voluntary sector 'services', community networks and informal carers play in reducing these barriers?
- What are the experiences and 'pathways' of those who are just starting to face challenges to their independence and well-being (and their supporters)?
- What is the learning for a whole system approach to early prevention?

**Stage 1** of the project was an evidence review, which identified, reviewed and critically appraised the Welsh and wider UK literature in relation to the above questions (Blood, Copeman & Pannell 2015). We focused on carers and older citizens, and especially on those who are not already engaged with services. This informed our approach to **Stage 2** of the project.



The following five themes came up time and time again throughout our evidence review and are discussed throughout this report:

- Having choices and being in control (including having the right to take risks);
- Having a strong sense of identity, continuity and belonging;
- Coping with worry and uncertainty;
- Planning for change and transitions; and
- Feeling socially connected.

In our evidence review, we started out thinking about the *barriers* older people might face. However, we soon agreed that more pertinent questions emerged from a more strengths-based approach:

- What are the secrets of success of those who lead fulfilling and independent lives in their later years?
- Which resources and personal strengths are most relevant to us at this stage of our life course?
- How can we understand the *anatomy of resilience*?

## **1.2. The 'anatomy of resilience' model**

Our evidence review identified seven core themes, presented in the wheel below. This model offered a starting point to describe and understand the 'anatomy of resilience', which we discuss throughout this report: the things that help older people to retain their well-being and independence and reduce the risk and impact of crises.

## The anatomy of resilience



After our initial scoping of the literature for the evidence review, we added a further theme of **'Work and Learning'**.

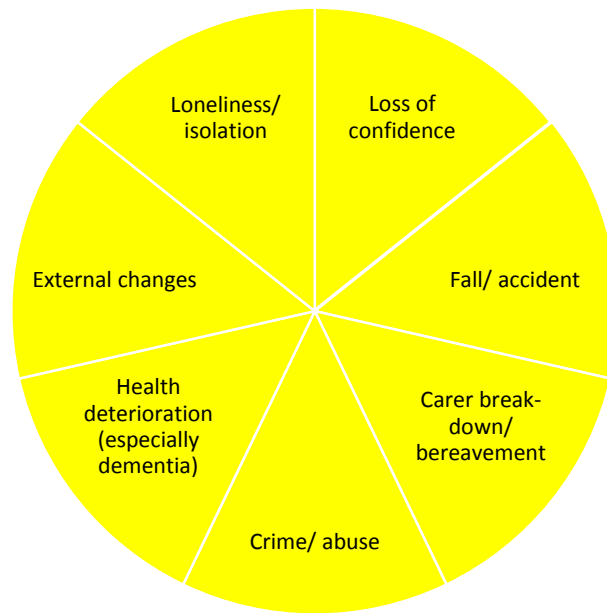
### 1.3. Understanding the crisis triggers

One of the aims of this project is to try and understand the experiences and pathways of those who may be on – or approaching - the cusp of needing services. How can our 'anatomy of resilience' model help us to understand the crises that typically lead people into services'?

In our evidence review, we identified the most common pathways that lead older people (unplanned) into long-term care. We developed the parallel model shown below – effectively an 'Anatomy of Crisis' with a focus on the key events and circumstances from an older person's perspective.

Some of the segments of this model describe incidents – falls, accidents, bereavements, or experiences of crime - that may change a person's resilience and well-being overnight. Others are typically *gradual processes*.

In this report, we draw on our interviews and focus groups to consider how the crisis triggers operated – or how they were avoided (sometimes as 'near-misses') - in a number of short case-studies.



#### 1.4. Where we went, who we spoke to

In summer and autumn 2015, we went to different parts of Wales to hear the views of 135 people; most were not in touch with Social Services. We conducted focus groups and individual interviews in five rural and urban areas across Wales. The majority (67%) of participants were female but, given that men are often under-represented in older people's groups and services, we felt this was a reasonable breakdown. 68% of the older people we spoke to were aged 75 or over, and most had longstanding disabilities or health conditions.

#### Carers

We were asked to speak to 100 older people and 30 people caring for older people; however we were soon reminded of the considerable overlap between these two groups: many of the older people we spoke to were caring for partners, siblings or even parents. 22 people were interviewed as carers, and a further 30 of the older people we spoke with also told us that they were carers.

We have highlighted the issues that are particularly relevant to carers in section 3.3 and 3.4. As many of the issues identified applied to both older people and to carers, albeit in different ways, we felt it was important to reflect carers' voices throughout the whole report.

## Ethnicity

We had conversations with people in English, Welsh and Somali. Nearly half our participants identified as Welsh, and one-fifth identified as speaking Welsh or Welsh and English. Ten respondents identified as Black or Asian and four as White European. This included a small focus group of five older Somalian men. We also met other older BME people informally at information events and social groups (who did not provide demographic data), including over 20 people at a social group for older Black and Asian people.

In autumn 2011, we interviewed seven older Polish people (all aged 85 and over) living in a retirement village in North Wales as part of a separate study for Joseph Rowntree Foundation exploring the decision to move into housing with care (Pannell, Blood & Copeman 2012). They included a widow, a widower and four couples: three wives and one husband were caring for their spouses. Most had come to the UK during or soon after the second world war. Most knew of this specialist scheme some years before, and had planned to move there if or when their health started to deteriorate: one woman said that she and her husband had decided "if we get old we will come here and become part of this community" because there were few Polish people where they lived. All chose to move so that they would have access to company, social activities, support and care from Polish speakers, a Polish church and Polish food in the on-site restaurant.

We have included these earlier findings in this report, as they provide a valuable insight into what matters to older people within the Polish community.

We are mindful that the sample size of older people from black and minority ethnic backgrounds, although representative of the Welsh population, is too small to make reliable comparisons with white Welsh or white British older people. There were, however, experiences and issues which were particular to or more pronounced for older people from black and minority ethnic backgrounds and we have identified these throughout the report and in a stand-alone section at 4.6.

## 1.5. A note on language

Throughout this project, we have worked hard to stay grounded in the language of ordinary people. Our ultimate aim was to build an evidence base to inform a more 'preventative' approach to service provision or, put simply, approaches which seek to maintain or maximise people's independence and well-being. However, we were asked to find out and feed back how older people see the world and not to filter this through the viewpoint and language of services. We ask what matters to older people, rather than seek to define 'outcomes'. We explore what helps and what gets in the way, rather than identify 'their needs'.

We are aware of – and broadly support – the arguments that it is 'interdependence' rather than 'independence' to which most people truly aspire (Solvieg 1999). However, those we spoke to were often quick to articulate what 'independence' means to them and why it matters so much. As we outline in the next section, this was often about getting the balance right between reliance on others and being able to make a contribution to these relationships – in others words, 'interdependence'. It was also about being free from interference and being able to choose how to live your life.

The Social Services and Wellbeing Act places a strong emphasis on 'prevention'<sup>1</sup> and this report gives us insight into the day to day things that matter most to older people and help them to keep well. A key message from this research is that, rather than taking a service-led approach (which tends to focus on finding service-based solutions to keep people out of the most expensive services for as long as possible), we need to start with people and the networks to which they belong and ask how we can best support them to achieve and sustain the things that matter most to them in life.

There are examples throughout this report that can help professionals start thinking about the kinds of person centred preventative services that have helped older people; the most effective and useable services are always those that people themselves have helped to shape, (as in Department of Health 2008).

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<sup>1</sup> See SSWB Act Code of Practice, especially chapter 3  
<http://gov.wales/docs/dhss/publications/151218part2en.pdf>

## Chapter 2. What matters most to older people and their carers?

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We started many of our conversations by asking people what a 'good day' looked like for them. They talked about not being in pain; about being able to get out and about; about good weather; and about simply waking up and finding they were still alive. Many told us about the people they would choose to spend a 'good day' with – partners, children, grandchildren and friends.

In this chapter, we consider the fundamental things which older people told us they valued: the things that were ends not just means, to them. Money, for example, tended to be valued because it could, in some situations, bring choice and greater independence. In the language used by services, these fundamental building blocks of a good life might best be described as 'outcomes'.

### 2.1. Being independent

Many of the people we spoke to told us that they valued being independent. The prospect of losing your independence tended to provoke great fear and those who felt they had already become dependent in some areas of their lives described a sense of loss. The Social Services and Well-being Act Wales 2014 (Part 2, (6) 3) stresses 'the importance of promoting the adult's independence where possible'. But what does 'independence' really mean to older adults?

#### Not having to rely (too much) on others

People were often very conscious of the potential impact of their deteriorating health on those around them:

*"ot being a burden to anyone..... when you can't do things for yourself like you've always done you feel you are a burden to keep asking people; although my family keeps saying 'just ring, Mum' – people have got busy lives today"*

Some explained that being independent was central to their identity:

*"If I have to become dependent I won't want to live..... I'm a bachelor, I'm used to being self-sufficient."*

## Being able to get out and about when you want to

Not having to rely on others in order to meet basic needs was a key part of being independent – for example, not needing someone else to take you to do your food shopping. Being independent was about being able to do the things you want to do, when you want to do them.

*"In regret that I am very dependent on family to take me out. I was very independent when I was younger – I brought up my children almost all on my own because of my husband's work."*

## Being able to move around in and maintain your own home

People described being able to get in and out of the bath, or up and down the stairs by themselves (sometimes with the help of aids and adaptations) and how this promoted their independence.

For some, being able to keep their home in a good state of order was important:

*"Do your own chores"*

*"One of the joys in my life is housework – I love to clean – and I clean my house on a Wednesday – I just feel that I couldn't let anybody take that from me. I think to myself 'I couldn't have anybody in here doing this because they wouldn't be doing it like I do' "*

## Avoiding going into a care home

For a number of people, 'losing independence' was synonymous with "having to go into a [care] home". This was something that most people seemed very keen to avoid; some to the point of saying they would rather die.

However, these kinds of fears could become a barrier to asking for or accepting any help at all:

*"When they ask me how I am, half the time I'm telling lies – I've got this fear that if I tell them too much, they'll put me in a home – I want to die here."*

For many people, though, the desire to remain independent (and within that avoid residential care) had been the driver for being proactive and planning ahead – getting adaptations made to their homes, moving house or making sure that their social networks were strong.

## **For carers: trying to promote the independence of the person you look after**

One interviewee told us how challenging it was for the paid carers who visited her mother (who has dementia) to support her in a way that promoted her independence: there is simply not enough time in their short visits to encourage her to wash herself and brush her own teeth. We will return to this point about the response of services in chapter 5.

Some of the family carers we spoke to also described the balancing act of trying to support the person they cared for without undermining independence. Two young women who provided care for their grandmother who lives with them in their family home reflected on this challenge:

*'We've possibly made life too easy for her ... she didn't even want to try to do things for herself ..... she gets anxious if she is on her own for too long'*

## **For carers: the impact of caring on your own independence**

We had an interesting conversation with two women who had cared for their partners: both felt that this experience had in many ways increased their own confidence and thus their independence. The reversal of gender roles later in life sometimes meant that women had become the lead driver and money manager in their partnerships, where men had had to run the home. Such role reversals can improve the carer's skills and confidence, and hence their longer term capacity for self-sufficiency.

However, at the same time, many carers described being very tied in a way that limited their independent life and interests. One man was seriously restricted because he could not leave his wife at all:

*"As the health deteriorates so you find as a carer, you are completely confined. I couldn't leave her for more than five minutes at any time. She couldn't come with me shopping, I couldn't go out anywhere, I couldn't get out into the garden to do anything there so the garden became overgrown."*

One of the two women we mentioned above told us that, since her husband (who has dementia) had moved into a care home, she felt she had a lot more independence – in the sense of having freedom:

*"I've been a carer throughout my life ... I brought my children up ... then cared for my mum ... then my husband ... I am actually MORE independent now [he's in a home]."*



## 2.2. Feeling good about yourself:

People talked a lot about 'being happy'; often this involved being able to continue to do 'your thing', 'keeping your mind', and maintaining a strong sense of who you are. A significant number spoke about their faith and spirituality as playing a big part in this.

*'Allah still gives life'*

Some described the challenges of retaining or re-establishing your identity in the face of deteriorating health and ageing: one person told us how important 'staying young at heart' is; another told us they felt 'exactly the same' as they did when they were younger. Some of the people we spoke to seemed to have a strong personal narrative – they saw meaning and purpose in the way their life had unfolded. For example:

*"I'm completely content with life. All of it has prepared me for what is coming ahead."*

This theme is closely linked to the previous one, since independence is often connected with pride and self-esteem. For some people it seemed very important that their narrative was as someone who has always taken responsibility, and been self-sufficient: 'we have worked all our lives'. One man explained:

*"I think the fact that I was 70 years in the service (RAF) helps that. You have to learn to be responsible for yourself. You can't rely on handouts".*

A recurring theme in this research as in similar projects (Blood 2013), is the ongoing – or even heightened – importance of being able to make a contribution as you get older. Many of those we spoke to were active volunteers, and they wanted to make a difference, remain useful, and challenge themselves.

One woman told us she has been looking after one of the communal garden spaces at the sheltered scheme where she is a tenant. She asked a neighbour who has dementia to do it with her:

*"now she and I buy the plants and do the garden together ... it's her thing ... something she looks after."*

Having to ask for help, or be on the receiving end of care – especially when you are the one who has generally looked after others – can be very challenging for people's self esteem and sense of self.

### 2.3. Being connected to others

Relationships are a fundamental building block of a good life. Those who had good relationships with partners, family members and friends told us how much they valued this companionship and emotional support. One woman told us that a 'good day' for her involved going out to a garden centre or café with her daughter; another described her young granddaughter as her 'little friend'.

However, there was huge diversity in the relationships that mattered to people: for some, friends were at least as important as family; others valued contact with younger people outside of their family (through their involvement in Scouts, Guides, the chapel or the mosque); and many seemed to be sustained by low level informal relationships, with shopkeepers, other passengers on the bus or a neighbour who passed tomatoes over the fence.

We met many people who clearly thrived from their very active social lives, often linked to key roles in their local communities:

*"I was previously a Councillor, at county and town level; this occupied my time and meant I got to meet a lot of people."*

Those who felt that connecting with others was central to their well-being were concerned about others who did not seem to want to make the effort:

*"It's easy to get lost and go into your shell...the individual must make the effort and be encouraged to do so."*

However, some people told us that they (or others they knew) had always 'kept themselves to themselves' or had never wanted to socialise in groups, reflecting the discussion in our evidence review about research findings on the differences between 'joiners' and 'loners'. Some of these people seemed to be happy introverts:

*"I had a neighbour who I used to talk to over the garden fence, and he was certainly isolationist – he didn't want any interference from anybody. I tried to interest him in U3A [University of the Third Age] and he said "Oh no, no, no!" and as far as I was concerned he didn't meet anybody. He was only interested in his garden, making beer and that was about it; he was perfectly happy."*

Others were experiencing barriers to social connection, linked to disability, depression, poverty, or – in this case – ethnicity:

*"I don't know many people – neighbours – it's more difficult because I'm Asian and Muslim, though I do know a few people".*

There was so much material on people's relationships, including the rich conversations we had with family carers, that we have dedicated chapter 3 to this topic.

## **2.4. Staying active**

A central element of well-being was being able to participate in interests and pleasures which give structure and meaning to life.

Some described 'feeling free' on retirement; others struggled with suddenly being a 'nobody'; however, many of those we met were determined to continue living a full life in retirement. Some people were involved in a range of activities, which sometimes included staying physically active:

*"I like to be fairly active, so such things as gardening, swimming, even going out and doing a bit of exercise always contributes to a feeling of well-being".*

A Somalian man in his eighties told us that he regularly does decorating for family, friends and members of his community. He told us that going up and down the ladders all the time helps him stay active – he worked all his life as a seaman and is keen not to be idle.

Others told us they enjoyed challenging themselves with new voluntary roles or formal learning. We spoke to a number of people who were involved in the U3A (University of the Third Age), or had taken computer or Welsh language classes. One woman who had given up work early to care for her aunt and her mother had, when they died, done a degree with the Open University, because *"I wanted a challenge, particularly after being around those with Alzheimer's - that was very hard"*.

But not all the examples of interests and learning we heard involved formal courses or group-based activities: others pursued their hobbies and passions at home or outside of organised activities:

*"My husband makes walking sticks in the garage and he does the garden."*

*"Being able to enjoy the beautiful surroundings we have around here."*

*"Doing some exercise – on my exercise bike."*

*"Music has dominated my life – I still play the piano."*

A number of people talked about the importance of giving structure to their day or week in order to stay independent and well. Some people felt that having regular events in the week helped:

*"Being able to say 'well, tomorrow is whatever day and that's when I go to the Centre."*

For the Somali men we met, an extensive schedule of prayers and classes to improve their understanding of Islam at the local mosque provided structure to each day.

Others had personal routines and rituals which were important to them:

*"At 4.30pm on a Friday I always like to sit and have a Gin & Tonic and a packet of crisps! That's my start of the weekend if I am in the house."*

*"I walk into town every morning, buy a paper, go for a coffee and meet with a friend. In the afternoon I go home and cook a meal."*

Learning to adapt practically and psychologically was felt to be an important factor in remaining active and resilient, especially for those who were facing health problems.

*"My husband had heart failure.....it's taken a bit of time to get used to not being able to do everything that we used to do, but we do try to keep active."*

## **2.5. Being well**

Physical health was viewed as both an enabler (or a barrier) to achieving the other things that mattered to people and as a key outcome in itself.

*"Health is all that's needed."*

Being pain free – or at least managing pain so it is bearable – was a recurring theme. We were surprised by how many people, when asked what a good day involved for them, immediately responded by talking about a lack of pain. Conversely, some people told us that they or their partner were in almost constant pain. We got the impression that pain is not always picked up on or taken as seriously as it might be, by the medical profession or by social care workers.

*"I'm always in pain walking.... I take paracetamol – should I see a specialist?"*

Problems with mobility, sight, hearing, or dementia were often mentioned as getting in the way of being able to get out and about, to connect with others and stay active. People also talked about energy levels and memory.

One woman who had a fluctuating health condition explained that there are lots of times when she cannot go out because of her health: *"I get very down about it"*. She told us that it was important to make the most of it when she is feeling better: she and her husband go abroad then, or go to Centre Parcs.

Feeling safe and secure was mentioned by many – both safety from crime but also feeling that there was someone to call on in a crisis, or someone to come if you had a fall.

Maintaining your confidence was felt to be vital here – people told us about friends who were afraid of going out on their own in case they should fall, which created other challenges in terms of their mental and social well-being. We heard how some people refused to use walking frames, sticks or hearing aids out of pride, embarrassment or stubbornness. Others described sheer determination in the face of physical adversity: one woman was already up and walking on her new hip, despite having severe rheumatoid arthritis.

A key part of being well also involves managing worry and anxiety – about health, about money, about the future, about death, about little things:

*"I worry more – I don't worry about the future – I worry about stupid little things – it's hard to say – and I'm slowing down and I can't do the things I used to do and I think that worries me but there's not really anything to worry about."*

*"Death is more and more on my mind, as some of my friends start to die. I can't help but think, 'Will I be next?'"*

## Chapter 3. Relationships

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Although 'relationships' appear as one of the segments in our model on p.10, there was so much discussion about relationships – between partners, parents and adult children, 'carers' and 'cared-for', and neighbours – that we felt this warranted a stand-alone chapter. In it, we present some of the common themes and issues in these relationships: what helps families adapt to the challenges of deteriorating health and what tends to cause strain or even breakdown? We also present the key messages from carers about the support they need in order to care for partners, parents and other family members in a sustainable way.

### 3.1. Partners: bereavement, loss and new beginnings

Bereavement and loss were, perhaps unsurprisingly, recurring themes. 40% of those we interviewed lived alone and this increased to 53% of those over 75 years old. Some of these people were single or separated, but the majority had been widowed. Some talked about the isolation and loneliness they felt after their partner's death, which could be particularly pronounced where they had cared for them:

*"After my husband died, I wanted to keep going to the Alzheimer's Society meetings, but you're not allowed to go there anymore. After he died, no-one contacted me – the doctor, the social worker – to see if I needed any help – I have no family except one niece in Birmingham."*

Another woman described the loss of friends she experienced on becoming a widow:

*"When my husband died, a lot of friends vanished, especially couples who found it strange now that I am on my own..... you get a bit forgotten."*

Others explained that they felt 'nervous' going out since losing a partner. In one extreme example of this, someone who ran a lunch club explained that one woman came along to their group and told them *"it was twenty years since she had been in anyone else's company..... she hadn't ventured out since her husband had died."*

Some people felt they had effectively lost their partner to dementia, even though they were still alive. One woman told us that her husband had been living in a care home for the past four years and that sometimes, when she went to visit him, he could not even speak. She told us how much she depended on her friends and acquaintances for stimulation and support.

We also heard of new romantic relationships. One woman explained that she had left her abusive husband in later life and was now very happily married to a man who had lost his teenage child in an accident. She explained:

*"We have both had tough lives..... So now we are together, we can look after each other and have nice times – we go on as many holidays as we can afford."*

Like this couple, several people told us they had been married two or more times. For some, this had created complications and tensions with other family members. One man told us that his first wife had her share of his occupational pension when they divorced, which meant that his second wife would not receive a widow's pension in the future (and he was more than 30 years older than her so likely to die first). Another man reflected on the impact of the age – and health - gap between him and his partner:

*"My partner is 8 years younger than me - she is marvellous for her age, in pretty good health, so I can't keep up with her! She doesn't need me for company. I'm lucky, she looks after me well, but she's out a lot ... so I'm on my own quite a lot and I've got to do something about it."*

### **3.2. Relationships with children**

Some people enjoyed regular support from adult children who lived nearby (or even in the same house); but others did not have children, or found the relationships less supportive, because of tensions or geographical distance. Some people told us they did not have any family at all – generally they were very old and this had sometimes been as a result of the World Wars. Others were estranged from family and there were a couple of instances of adult children having died.

A handful of people had children who lived a very long distance away – some as far away as India or Canada. We heard how this could be mitigated by good communications: a nightly phone call or regular use of Skype, for emotional support and company.

Many people told us their children did what they could to help, but they were very conscious that they are busy with their own lives. One woman told us that her daughter and son-in-law live 10 miles away, but they both work and are busy with their children. Although she seemed to accept her daughter's busyness, she was also saddened by the lack of quality communication she has with her as a result:

*"My daughter also prefers to text than phone and I am the other way round – I told her something the other day and she said 'You've told me that already'."*

Many people worried about asking too much of their children. We did, however, hear very different expectations on this question: some people were clear that they would much sooner ask their children for help than strangers or services, where others were more anxious about over-stepping the boundaries or 'putting too much' on their children:

*"I decided I wasn't going to rely on my children because my mother-in-law put on us so much – if you tried to go anywhere she would be ill, that sort of thing .....so I didn't want them to feel as though they had to have me..."*

A few people commented that their daughters (and even daughters-in-law) were more receptive to offering help than their sons. One woman explained:

*"I'm always conscious of relying on my daughter too much so I would like to know how to get my son to help out more, especially with driving me to places. The thing is how do you put it over to them without hurting their feelings? A son doesn't understand the same as a daughter, do they?"*

Some people told us that their children had put pressure on them to move to live close to them. Where they had been able to build new social networks (due to factors such as health, personality, location and still being able to drive or access transport), this seemed to have worked out well; but there were other instances in which this had not happened and they now regretted making the move. We met one woman who was in her nineties and had left a town in England, where she reported having a good social life, to live in a sheltered housing complex near to where her family lived, but where she had struggled to make new friends. She described the move as 'her family bringing her here'.

Conversely, we heard how some people had moved to Wales either to take up a job or on retirement, leaving family behind them in England. For this group, there was a risk that retirement, health problems or having to give up driving could trigger isolation.



### 3.3. Becoming a 'carer'

Some of the people we spoke to were caring for a partner, parent or sibling – or had done so until they had died or moved to a care home. For some of this group, their caring responsibilities were more or less around the clock and they described being very tied or having few opportunities for a break. One woman, whose grandmother had lived with them while she was raising four children explained: *"I used to hear her calling out in the night all the time.....if you don't get your sleep, you can't cope with anything."*

Those who were caring for someone with dementia at home also described significant emotional difficulties in addition to the practical and physical challenges of their role. One woman explained that her father cannot speak on the phone because his wife (who has dementia) gets very jealous. Another woman who is caring for her husband with dementia told us that it has become increasingly difficult for her to do practical things around the house and garden since her husband wants to 'supervise' these things. Not only does she have to do all these practical tasks, but she also has to *"find new ways of doing things that don't lead to conflict"*.

It was not only dementia which could affect the personality of the person being cared for. One man, who was looking after his wife, explained that:

*"She hasn't been the same since [the heart attack a year or two ago] and then because she's on the drugs it's affected her personality ...she looks after herself mostly, but there are times when the unpleasantness takes over and I need to get out."*

Some people described having to look after more than one family member at the same time. One man nursed his mother and his sister at the same time; another woman looks after her father, and her husband is now due to have a knee replacement: *"I'm going to have two of them to look after."*

For some, becoming a carer had involved significant role reversals. Sometimes this meant learning new skills:

*"I had to learn how to work the washing machine when my wife had her stroke – she thinks I know how to work it but I turn the dial and hope for the best!"*

For others, the shifts involved more of a challenge to their identity (perhaps more so for the person being cared for), and hence the challenges were emotional as well as practical.

Sometimes we heard how the person being cared for refused any outside help, which put more pressure on the partner or family member looking after them. We heard about a woman with dementia who refused to go out with the person who had come to provide respite; a man who could not hear because he would not wear his hearing aid; and parents who refuse to wear pendants which their children have purchased so they can summon help if they need it.

Some did not identify with the rather service-led label of 'carer', but rather felt they were just doing what they had promised to do in their marriage vows or were simply repaying the care their parents had given to them as a child:

*"I don't see myself as a carer, I just see myself as my father's daughter, he looked after me when I was a child, so is it not my time for payback?"*

*"With my mother I wore out five washing machines in five years with the washing I had to do because she was doubly incontinent, so you turn round and you do these things, but that was part of the family as far as I was concerned."*

There are implications for services using the word 'carer' if it is not a term people readily identify with. It may mean that information or support directed at 'carers' simply doesn't appear relevant to those family and friends who provide support.

## Caring for each other: Fred and Mary

Fred and Mary, both nearly 90, look after each other: *"He's my carer, I'm his but he can hardly walk, and I can't see."* Fred is in constant pain with many health problems including angina, bronchitis, pneumonia and prostate cancer. Mary is severely visually impaired because of macular degeneration and uses a white stick.

They have no family: like many of her generation, Mary was an only child; Fred was the youngest so all his siblings have died, and they had no children themselves.

*"We don't know any of the neighbours now, we've been there 60 years":* those who they used to know have moved away or died. They have no nearby friends, except someone Mary met at the social group that she tries to attend twice a month (but only if Fred is well enough to be left). When she attends the group, she comes in on the bus:

*"I like it on the bus because I meet people, sometimes they talk to you."*

Mary told us about someone she described as a 'best friend' who is twenty years younger than her but she lives a long way away. In the past they went on short dancing holidays together, but the friend now has health problems herself after a serious operation: *"I can't expect her to come and help me!"*

## Caring at a distance

Louise lives and works full-time in southern Europe. She supports her parents, who are in their seventies and live in North Wales, by phone and monthly visits:

*"I phone every day, sometimes more than once – usually I have to do counselling at a distance which is emotionally exhausting... I don't feel like I've abandoned them and I go more often if needed ... it's a two-hour drive to the airport and then two hours on the plane ..."*

Her father is primary carer for her mother (who has Alzheimer's) but she is in denial and unwilling to accept any outside help:

*"Things are getting more difficult too. I say to dad 'The time is coming when you will have to take her to a day centre – you can't carry on like this'. But mum has always made dad make promises and give up things ... I'm also trying to support dad and help him understand the illness and give him ideas to handle things. What I find difficult as a daughter is that he is carrying on behaving towards mum as he always has – I say to him 'You've got to put your foot down about certain things ...'*

*My brother gets frustrated because he gets people [from agencies] to phone but then dad closes up, because he can't talk in front of mum, but people think it is because he won't accept help! A few times I've been there when they've phoned and I've been able to talk to them, and I've said 'Why don't you write to him or make an appointment ... he's trying to cope alone and he worries'."*

### 3.4. What makes caring easier?

#### Mutual support

A clear message from our conversations is that it is much easier to receive care if you feel that there are also opportunities for you to provide support and make a contribution. If those receiving care feel happier, then they are also easier to care for.

*"Everyone needs to feel useful ... it's harder as you get older as you feel you can't be useful anymore ... being asked to do something when you're old is a really big thing."*

Some people described mutually supportive arrangements, for example one woman in her late 80s explained:

*"I have a daughter, but I'm independent. My neighbour helps me a little at home and in the garden...but I help her too – I cook for her."*

#### Acceptance

We heard that caring for people was much easier when they had been able to accept their changed circumstances and both parties were able to accept their new roles. This involved both the cared-for striking a balance between being over-demanding and refusing help altogether; and the carer having realistic expectations.

*"[How have you – and your mother – found the whole role reversal of you having to care for her?] Absolutely fine. Mother's been great – she knows she can't do things for herself now and she has accepted her limitations so she's never complained. Thankfully she still has all her marbles – I can't imagine how we would cope if she started to lose those. I think that would be the trigger for her having to go in a home."*

Having realistic expectations is also important in order to promote opportunities for the person being cared for to make a contribution. For example, one carer explained how she encourages her husband (who has dementia) to help around the house, but does not get stressed when he does things wrong:

*"He cleans [the house] sometimes, although he forgets where he's been...but that doesn't matter,"*

## Having interests and relationships outside of the caring relationship

Several full-time carers told us how much of an impact it made on their well-being when they were able to pursue their own interests outside of their caring relationship. One woman told us that she is able to pop out and leave her mother for a couple of hours in order to participate in a range of voluntary roles. Another has a very good friend who calls her every day and whom she is able to meet for coffee regularly. She feels she can confide in her friend and gets a lot of psychological support from her in her role as carer.

## Decision-making

We heard from our evidence review that carers often feel they need support in decision-making. In the research we heard how stressful it can be for families trying to reach consensus. For example, Louise (our carer at distance) told us:

*"What's difficult is when my brother and sister-in-law have different views from me. I was interested in [a specialist dementia housing scheme] or something similar...Dad went along and looked and he was very interested but my brother talked him out of it because it was too expensive."*

## Learning practical ways of coping with conditions, especially dementia

Louise also described trying to support her father around coping with her mother's dementia. So, for example, when his wife asks to go and see her parents (who both died many years ago), he will take her for a walk and, after a while, she has forgotten the original reason for going out.

In another conversation, we heard how the family of a woman with dementia had found a practical way to support her with remembering people's names:

*"For her 95<sup>th</sup> birthday, we got her a photo album of all the neighbours, the post-lady, her hair-dresser, people from the coffee morning and church ... so she can refer to it ... remind herself of their names and faces."*

### 3.5. The role of friends

We heard how important friendships are to many people. Two women who had been friends for over a decade had a shared experience of looking after their husbands who both had Alzheimer's:

*"We have been friends for years and she can see what I've been through ... we laugh about it [their caring responsibilities] together because if we didn't we'd cry."*

Some people felt that it was easier to ask for help from friends than family:

*"I think that friends are probably better than family anyway, because with family they feel as if they have to help you; whereas with friends, they tend to be more honest and will say if they can or they can't help you."*

We heard about the strong bonds of mutual support which still existed within many groups of older people – especially where people had lived in the same communities all their lives. The Somali men told us that, if someone did not come to prayers at the mosque for a day or so, someone would go and check they were alright. However, we also heard examples in which neighbours had over-stepped the boundaries:

*"I had a neighbour who once she got in the house you couldn't get rid of her – she'd be there day or night..... She was very lonely and wanted company, she'd lost her husband so she was on her own ... she was phoning at all hours and would deny it when I asked her; but now she's in a home – it was dementia. I had to have a word with her son in law – she was making me ill."*

We were keen to speak to men as well as women, because our evidence review suggested that older men may have different needs and perhaps be at greater risk of isolation. Our impression was certainly that women were much more likely than men to join older people's clubs. However, we also met a number of men who had made a conscious effort to socialise. One man told us how important it was to him to continue to spend time and play golf with his former work colleagues: he was clear that he did not wish to go to clubs and activities with people who were older than him. Another man told us:

*"After I lost my dear wife I thought well I've got to do something so I joined a Welsh male voice choir and never looked back since – even sung at the Albert Hall in London. So we are out three or four weekends with that; odd times in the week as well; we rehearse every Monday. I'm not saying I'm lazy but it's easier not to cook, I go and have lunch most days down at the Cambrian Arms which is about two miles down the road from me, where they*

*provide a very good meal every lunch time and I meet three or four chaps down there and we have a good chat and pull everybody to pieces. And because I go there, they persuaded me to join the Dominoes' team, so we play Dominoes once a week."*



## Chapter 4. What helps or hinders older people in achieving well-being?

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We have heard what older people and carers said they value most. In this chapter, we look at some of the things which either help or hinder them achieving these outcomes: issues like transport, where they live, technology and equipment. We will explore people's pathways through and perceptions of statutory and voluntary sector health and social care services in the next chapter.

### 4.1. Transport

86 out of the 130 people we spoke to told us that they had access to a car. This was true of 63% of those who were over 75 years old, with men (86%) being more likely than women (53%) in this age group to have access to a car.

Most of those who were still driving explained that they tended only to make local trips – mostly to get shopping, attend appointments or go to clubs. Whether or not you could park close to where you need to go – especially when carrying bags of shopping – made a big difference: pedestrianised town centres and a lack of accessible parking at hospitals and surgeries created challenges.

Those who were able to drive told us that being able to make trips in their own car was key to meeting basic needs and facilitating their social lives and interests, especially in areas where public transport was poor or where people lived in remote rural locations:

*"I'm still driving and in fact it's a necessity really because even if I went to a local shop you are talking about a drive for 2 miles, and when I say a local shop I mean it's a petrol station with convenience food. But if you wanted to buy clothing and whatnot, you are talking about a 14-mile drive."*

Some people told us that they were really worried about how they would cope when they (or their spouse) could no longer drive. For some, the risk of isolation was high, but often it was the fear of having to depend on others for lifts or to fetch your shopping which was felt most strongly. Health problems or bereavement were often mentioned as the triggers for giving up driving, though many described the decision to stop in terms of losing confidence:

*"It's how I feel – I'm within the limits for my eyesight but I worry about my balance – one day I was coming out of a corner and I went over the kerb. And then my daughter said, 'Mum, I don't want you driving with the kids in the car' – well, that didn't help my confidence. I was sure I was ok really but then I thought, if I have an accident, I'll be to blame."*

Money was a key consideration for some people who said they could no longer afford to take taxis, run a car (especially given expensive insurance), or were put off by car parking charges. There was wide praise for the free bus passes for pensioners. However, our findings confirmed those of previous research into public transport in Wales (Mackett 2014; WRVS 2013). People described: a dearth of services in the evening (or even the late afternoon); problems getting to hospitals; a lack of bus shelters; and problems accessing bus information.

*"I have a bus pass but rarely use it because there is no bus kiosk showing all the services ... you have to ring all the bus companies up individually."*

Some people told us they used their local community transport schemes, but many more described barriers here: services were over-subscribed; charges seemed relatively high; and people were put off by the fact that you needed to plan so far in advance. Above all, people reported that it was difficult to get information about such schemes. One woman told us that she had been spending £30 a trip going to visit her husband by taxi in a care home, until she found out by chance through word of mouth about a Car Link scheme, which cost her £10 instead.

Many of the older people we spoke to – especially those who attended groups or churches – described a strong network of lift-giving:

*"When I couldn't drive [for six months following a heart attack] someone from the group here often gave me a lift – it's good like that, people help each other out."*

## 4.2. Home environment

### *Staying put*

Most people saw continuing to live in your own home as being key to maintaining their independence and control – a number expressed determination to avoid a move to a care home:

*"I try not to think about it, frankly you don't want to leave home if you can manage it."*

### *Accessibility*

Some people described challenges moving around their homes, particularly in relation to getting up and down the stairs and in and out of the bath. For some, these had been temporary – whilst recovering from a fall, operation or illness:

*"I had to go up and downstairs on my bottom – I've got no downstairs toilet. There's nowhere here to put one unless we build on and I couldn't afford to build on. If it ever came to it I suppose a stairlift would be the only answer."*

Some others, with ongoing mobility problems (and those caring for them) told us that they had managed to get aids and adaptations such as grab rails, stair lifts and bath raisers fitted – sometimes through Occupational Therapists or Care and Repair, and sometimes using their own money. Sometimes, as in this woman's case, adaptations made for her husband had made a huge difference to her own ability to bathe and move around the house independently:

*"I have trouble getting in and out of the bath – at one stage I was going to a day care centre to have a bath in their adapted bathroom – but it wasn't ideal, I don't really like having a bath in the middle of the day and the second time I went there wasn't any hot water. Then I think it was through the OT who came to visit [my husband] after his operation, they helped us to get a machine so we can get in and out of the bath and that's made a big difference.... And we got various grab rails and handrails which I use all the time."*

### **Prevention good practice**

*"The district nurse came to the house because of his incontinence, she saw the handrail and got us a stronger banister."*

## **Location**

We have already considered some of the challenges facing the older people we met who were living in very remote rural locations, but some of those living in more built-up areas were also at risk of isolation where they lived at a distance from local facilities and public transport, or were marginalised because of culture, language or money. In addition to these logistical questions, people's feelings about the location of their properties were also strongly influenced by their sense of belonging, of community safety and whether or not they enjoyed good relationships with their neighbours. We will consider all of these points in more detail in the following section on 'neighbourhoods'.

## **Maintaining and heating your home**

Some of the people we spoke to were living in houses which have large gardens or presented other challenges in terms of maintenance. This was becoming a challenge for some. In one extreme case, we went to the home of an older woman who was dealing with the aftermath of a water leak. Her main worry was the cost of the £300 excess on the insurance claim:

*"How can I save up that sort of money? I own the house but I have got all the bills... ."*

Many expressed concerns about finding reliable and trustworthy practical help – both tradespeople to work on bigger jobs, but also 'that little bit of help' which is frequently flagged up as a priority by this age group (e.g Raynes et al 2006, NAO 2015).

For some lower income home owners (like our woman with the water leak), the *cost* of maintaining and repairing their home creates a barrier. We spoke to a significant number of homeowners who had used Care & Repair services (and we will return to this point in chapter 5). They had received grants through them for a new boiler or were having alterations done to make their homes accessible (such as ramps, grab rails and bath lifts).

Others were willing and able to pay, but had concerns about the supply or quality of tradespeople or ongoing low level help in the private market, or how you would go about finding such tradespeople or help.

*"...also who would do the work? Oh yes, I would only go with somebody I knew, I'd be terrified to have somebody come in that I hadn't been recommended... ."*

*"If you could get good carers privately or good cleaners and gardeners, you would be able to stay in your own home forever... ."*

Several people expressed uncertainty about their current and future **utility costs**. Some people told us that they could not afford to have the heating on much and that affected their joints and other conditions. We heard that, in rural Wales, many people need to use oil for heating. At the time of our fieldwork, costs were falling, but people were concerned about the impact if and when they rose again. Unlike for gas and electricity, longer term price plans were uncommon.

*"I mean for heating around here it has to be oil unless you are in the town. At the moment for about a 1000 litres is about £400.00 – it was £600.00 not that long ago [goes on to make the point that this could change in the future...]"*

We discuss the wider question of money and how it can support or impede well-being in the section on money.

Many of those we spoke to told us that feeling safe and secure in their home was another key factor in contributing to (or detracting from) their well-being. We consider this in more detail in the following section on neighbourhoods.

### **Moving out**

A significant minority of those we spoke to had taken a planned move to a smaller or more conveniently located property, or into specialist housing for older people.

There was discussion in some of the groups about various forms of extra care housing, which was generally felt to be a much better option than a care home, offering more space and independence. One participant noted the difference between an extra care scheme and the nursing care home he had moved his mother into:

*"I wish I'd known about this [extra care scheme] for my mother. It isn't easy being in communal living, I know I would hate it.....If I compare where my mother was to this ... she only had a little box room... ."*

However, others were concerned about the ongoing risk of social isolation within extra care housing developments. Participants at one focus group discussed a nearby extra care scheme. One person told us:

*"my friend went there for more social interaction but she's not getting it because no one is going to things...some of them are getting their meals taken up... ."*

However, another participant in this discussion observed that:

*"...It is about having choice because otherwise it becomes an institution... ."*

Around eight of the older people we spoke to were living in sheltered housing: most of them were really glad they had made the move. One woman explained that, although her flat was 'tiny' compared to her previous home, it is 'so convenient!' Others told us they felt much safer and were enjoying the new friendships and opportunities to mix within the scheme. Several of the Somali men we spoke to were living in a sheltered scheme which had been specially built for Somalian sea men. They described the support they received from staff (including a daily meal) and the social interaction they enjoyed with other tenants and members of the community living locally in the communal lounge.

However, many of those living in sheltered housing felt that these benefits were being threatened by cuts and changes to the warden service and by the practice and policy of their housing provider. Examples included not allowing residents enough control to organise simple things like their own laundry rota or support workers who let themselves into your flat without giving you time to answer. The reduction in warden support meant that some felt socially isolated or less secure. One group recalled a story of a lady who had fallen and had not been found until the following morning because the warden was now only there until midday when they had previously lived on site. One woman, who had been caring for her husband within the scheme until his death, explained:

*"Since I lost my husband there is no one to talk to there.....It's nice to have the warden on the place, someone you can depend on."*

Others had 'downsized' within the general housing market, or were hoping to do this. The number of bedrooms is generally the focus of policy discussions about 'downsizing', but for most of this group the key features that they felt would support their independence were accessibility, location and ease of upkeep:

*"...we had a big semi with a big garden, one day my husband was up steps pruning the apple tree and we both decided that we couldn't cope any longer so we sold up and rented temporarily until we found this bungalow... It's lovely – there are two bedrooms, and a huge wet room with a bath as well as a shower and designed for wheelchairs. We have big double gates into the parking in the garden, and shops nearby (though it's a bit hilly) with a dentist, GP, chemist and a bus every half hour and all within five minutes' walk."*

Some homeowners told us they wanted to move to towns and/or smaller properties, but felt blocked in this by **the housing market**. Some were struggling to sell their homes: they felt that prospective buyers were being put off by the house price rises of the last few years and what they saw as overvalued council tax bands. Others had considered moving but told us that they had not been able to find anywhere suitable to move to in terms of location and affordability.

### 4.3. Neighbourhood

There were three different aspects of neighbourhoods which older people told us either help or hinder their well-being: the availability of local facilities; the sense of community safety (or the fear of crime); and the sorts of relationships they had within the local community.

#### *Local facilities*

Some people told us that their local shops and post offices were closing down or were under threat and they were concerned about the impact this would have on them and the local community. Others felt that cuts to a range of public services – street lighting, public transport, local advice centres, libraries, local hospital services and sheltered housing wardens – were threatening older people’s capacity to remain independent. People told us that they particularly valued libraries as a source of help and support around accessing computers, especially the fact that this help was available on a free, drop-in basis from helpful staff. Welsh-speaking groups in rural areas felt the closure of chapels and churches keenly. One explained that “*The chapel was the society*”.

Problems with accessibility also made using some community facilities challenging, off-putting or sometimes impossible.

*“Last time I went to my local theatre, there were no handles or rails or anything by the toilet and I got stuck which was embarrassing and I went to grab the handrail up the steps and it was just a wire, and the seats are very low backed so there is nothing to hold onto as you are walking along the aisle..... it’s a confidence thing really – you lose your confidence, when you worry you might fall or not be able to get to the toilet, or get stuck when you do. When I am out and about, I’m always thinking – where’s the nearest loo if I need it?”*

## Missed opportunity for prevention?

*"The pathway between the properties at our sheltered housing scheme is a real worry – it is very uneven and has resulted in three people falling over already. Yet the housing association keep saying it complies with their regulations and so they don't fix it ... they don't see things from a senior point of view."*

## Community safety

Some of the older people we spoke to told us that they feel 'very safe'; but others told us of personal experiences (and hearsay) which had left them feeling uneasy. A common theme was that people now locked up very carefully where they had not bothered in the past – this was often presented as an indicator of a significant shift in community relations.

Some told us how signs of vandalism or children and young people swearing in the street made them feel that their community had changed and was no longer a safe place – a sense that was reinforced by a lack of visible policing now outside of cities. Others, however, critiqued the 'fear culture' which stops older people going anywhere after dark. A few people mentioned Neighbourhood Watch – most felt it was a positive thing, though others felt it was a sign of the times that it was needed (and neighbours would not naturally look out for each other), and one woman told us that hearing every police report for her local area at meetings just intensified her fear of crime.

## Missed opportunity for prevention?

*"One older woman I know was living on her own and unable to get up to answer the door. She had carers coming in and out all the time, so the door used to be left on the latch.... And people got to know this over time. There is the technology to sort the problem out – you can fit a voice call entry system with a buzzer – but social services said it was too expensive. It was only after she'd had two intruders (which had of course scared the life out of her) that the Police got involved and said they had the budget to fit the system."*



## *Relationships within the local community*

Some people had very good relationships with their neighbours and clearly valued this enormously. One woman explained that a neighbour had brought meals round for her while her husband (who is her carer) was in hospital. Others described looking out for each other - sometimes in an unspoken and natural way; sometimes through a more explicit arrangement:

*"Well when my neighbour first moved in, the first question when he came over for a cup of tea was 'What if I'm ill in the night?..... I'll tell you what I'll do I'll hit the wall and if you are ill in the night, you hit your wall!'. At least you know there is someone at the other end."*

In our evidence review, we heard how the 'shifting profile' of neighbourhoods can impact on the well-being of this generation. This was borne out for many of those we met in our fieldwork. People told us that they no longer knew many of their neighbours, due to a range of incomers: English retirees (especially in rural areas and small attractive towns); commuters (this was mentioned by a number of people living close to the border in North Wales); and East European migrants (mostly in the cities of South Wales). People felt there were a number of barriers to mixing with incomers: language in some instances, lack of time due to work and everyone having their own car.

Those living further away from the cities and borders were concerned about the steady exodus of younger people from their communities: *"They go to university and do not come back."* The Welsh-speaking groups seemed to feel the impact of an increasingly ageing community most keenly:

*"There must be younger people, or who will then maintain the society."*

*"There used to be so much more going on here than there is today."*

Changes to jobs markets, opportunities and expectations meant that many of those we spoke to had families who were very dispersed:

*"I've got five children and the nearest one is 250 miles away, the furthest one is 7000 miles away so there we are."*

There were a few negative comments about the behaviour of younger people, but the overwhelming and quite surprising sense was of a cohort of people keen to connect with those younger than them. The opportunities for inter-generational mixing were limited by: younger people's lack of time and work patterns; by issues around safety and transport which made it harder for older people to go out in the evening; by different lifestyles and use of technology; and – in some areas – by the sheer lack of younger people.

This intergenerational connection was felt to be key to maintaining the well-being and independence of older people in communities, especially in villages and smaller towns:

One very active woman in her eighties told us:

*"the other day it was blowing a gale and my door knocked, I opened it and it was Steve [a man in his forties who lives in my village] – he said 'have you got everything you want, would you like shopping or do you need to go anywhere?' I looked at him in amazement, I said 'no I'm fine' and he said 'would you say if you weren't fine?' I said 'I think I probably would, Steve' and so he said 'well that's ok'. Now that came out of the blue. If I'm stood at the bus stop in town and if he goes past, he asks where I'm going and says 'come on get in'. That's what I could expect but I couldn't expect that of anybody older because they can't do it so we need the affinity with the younger ones when you live in a village."*

However, some people reflected on the subtle and complex boundaries between neighbours in relation to what can you expect or ask of each other, and how this seems to have changed for some people. In one focus group, there was a discussion about whether or not, and in what circumstances, you might knock on a neighbour's door for assistance:

*"I don't know if I'd like to knock on somebody else's door – I'd be very cautious I should think to what their reaction would be."*

Despite the shifting profile of many communities and the relationships within them, people still described places which functioned as community 'hubs', where local people meet up and get to know each other. These included cafes, churches, mosques, pubs, community houses, the library, buses and even the local nature reserve:

*"Society has changed.....we are very blessed that we have got that nature reserve so, from tots to adults, they have access to that. It is a place to come together so that people know one another... ."*

*"I like it on the bus because I meet people, sometimes they talk to you."*

*"A lady on the bus this morning said she comes out everyday to go to town because 'I'd go mad sitting in the house!' ... xx Fish & Chip shop – she goes there nearly everyday! Five days a week she goes there."*

However, some 'hubs' had also been lost:

*"the shop used to be a buzzing hub of the village, but then the people who took it over immediately got people's backs up ..... now it's closing anyway."*

#### **4.4. Money**

Many we spoke to expressed concern about the current and 'new' state pension level not being enough to meet basic needs:

*"What is enough money? Well you couldn't live on the State Pension, well I couldn't anyway, not now.... No, it's a job to meet the bills now."*

*"I know I recently got 5 pence more for my pension ... but what is that? You can't even buy a pint of milk with it!"*

For many of those we interviewed, having an additional private pension was vital to their well-being:

*"I'm lucky that apart from my state pension I have an occupational pension as well so that gives me a reasonable income."*

Having and retaining some level of savings was also felt to be important, both for peace of mind and to cover 'lumpy' items – which, for many, including changes to their home so they can continue to live there independently (where public funding is not available or would involve a very long wait):

*"[If no grant, would you do the shower room anyway?] Yes, I'd have to because I can't get in and out of the bath any more, my knees are going and I haven't got the strength to get myself in and out and I'm living on my own so that is one of the greatest fears, that you're going to be stuck in the bath ... but once my savings are gone, they're gone and that's the worry, isn't it? I'm 82 ... I think our generation likes to have a little bit of savings, a bit of money behind you, I mean I could blow the lot but you think no way, you've got to hang on to it... ."*

Others felt that affordability would stop them taking steps to make themselves feel safer at home. For example, some recognised the value of having a personal alarm and pendant fitted but baulked at the ongoing cost:

*"I'm not paying £11 a month for that!"*

Some reported having lost an additional source of income, due to the changes to interest rates in recent years:

*"The only grouse that I would have is that savings with interest rates being so low – put it this way the interest I would get from my savings used to pay for my holiday."*

Being able to access benefits had improved some people's financial circumstances significantly. One woman who was supported to claim Attendance Allowance uses the money to pay a private cleaner (the niece of a woman she knows at a social activity) £32 a week. She described many benefits of this arrangement:

*"And it's company for me – she's very good, she does my shopping and makes my breakfast."*

However, being able to access good information and advice was essential here, otherwise people were often not aware of their entitlements:

*"We didn't know that we could get Attendance Allowance either – I was surprised. He qualified, and then because I was disabled I got it too. The Alzheimer's Society helped us a lot, with printed material and the memory café."*

We met some people who might best be described as being in the 'squeezed middle' financially. For example, this older owner occupier was just over the threshold for Pension Credit:

*"I'm a widow with old age pension and a small widow's pension but I can't get Pension Credit. I've got a small amount of savings but I've had to pay for loads of repairs – it's an old house - if it costs over a grand for the handrails, I won't be able to afford it. There's the children, grandchildren, birthdays, Christmas ... ."*

Some of those we spoke to were very restricted by poverty and this was clearly having a significant impact on their well-being, both in terms of anxiety and isolation:

*"I'm only just managing – that's because I don't go out ... I don't have holidays; I've got no social life – is there anything for old people like me?"*

The Somali men we spoke to explained that the fact they were sending money from their limited pensions to support family back in Somalia left them with little disposable income.

A culture of frugality was evident amongst some people; although not necessarily saying they don't have enough money; they have clearly grown accustomed to going without:

*"...if I can't afford it I don't have it."*

Yet people felt it was harder to control and plan their finances as they got older and were faced with increasing premiums for travel or car insurance and costs arising from poor or uncertain health:

*"When you're not healthy you have bundles and bundles of expenses, and everything is always going up."*

Others highlighted complex interactions between changing communities and the cost of living. One group highlighted the fact that money cannot buy good neighbourly support and, as this has decreased, help (such as a personal alarm or someone to do your shopping when you are ill) needs to be paid for. Others recognised that using budget supermarkets threatened the viability of the more expensive local shops, which in the long term would have a detrimental effect on the community and their own ability to live independently within it.

#### **4.5. Information Technology (IT)**

We met some older people who were using the internet to improve their well-being in a range of ways. This included ordering food and other shopping to be delivered online; using Skype to keep in touch with dispersed friends and family (and virtually attend graduations and funerals in other countries); and emailing other members of social and community groups. Significantly though, even regular internet users tended not to have used their computers to search for information and advice – a finding which echoes that of research with other groups, including younger people with sight loss ( Blood et al 2014).

*"[Do you use the web as a source of information and advice?] No, I have never thought of it to be truthful with you ... ."*

Some people said their children looked things up for them online; and there were one or two people who were more confident about searching:

*"[Would you use the internet for information and advice?]I would now because my family paid for a course to get me online, so I Google everything but before I wouldn't have because I dug my heels in and I regret no doing it sooner because it is so simple."*

Another man had gone online to read the Social Services and Wellbeing (Wales) Act before we met him:

*"And this is the problem with this Act [Well-being] – it hasn't been advertised – until you rang me up and told me, I didn't know, then I looked it up, and I go on the Welsh Government website on a regular basis but I didn't know this Act was coming in!"*

However, confident and regular users of IT were in the minority and tended to be in the younger cohorts (people in their 60s and 70s) and/or from middle class backgrounds; though there were individual exceptions to this. Barriers (or enablers) included:

**Fear of scams** was a key concern amongst this age group – some of the groups we attended shared warnings about scams. Most of those who had a computer told us that they would not do anything that involved money online, which clearly limits the capacity of the internet to help them with practical tasks like banking and shopping (though minimum orders for online grocery shopping was also a barrier). Some spoke of their (or others') experiences or fears of viruses, which had been expensive or troublesome to fix, and others were afraid of data privacy ('Big Brother'):

*"Computers frighten me to death: all the scams and everything!"*

*"I just browse – I don't do any banking or any buying or selling on there – I'm too nervous."*

**Knowledge, skills and confidence** in relation to IT varied enormously. Some of those in their 60s and 70s had learned to use computers while they were at work (especially those with professional or administrative backgrounds); others had accessed formal courses or had been taught by younger family members. However, there were criticisms here; some felt that it was difficult to retain the information which younger family members or formal tutors gave them.

**Cost** was a barrier for some: this included both the initial capital investment (especially in iPads and other tablet computers), paying for training or computer maintenance, and the ongoing cost of broadband subscriptions.

*"I'd like to do more – for example, with my photographs – I bought a Blackberry tablet thing but it's a bit slow for the internet really. It would be good to get a nice fast iPad like my son has but I don't fancy spending £400 for the privilege."*

**Poor connectivity** was a problem in some areas, especially more remote rural areas in West and Central Wales.

*"I find that it is very important that you should have good internet access and mobile phones, which we don't have round here."*

**Disability** also made it difficult for some people to access computers: several people mentioned that worsening eyesight made it hard to read the screen; others found it difficult to type due to arthritis; or were struggling to remember how to perform different functions because of problems with memory and cognitive processing.

#### **4.6. Black and Minority Ethnic Older People**

Some of the barriers reported by the older black and minority ethnic (BME) people we spoke to resonated with those experienced by white Welsh and British people and we have, therefore, woven these experiences and comments into the relevant sections of the report. However, there were some themes which emerged from our conversations with older BME people which were clearly linked directly or indirectly to their ethnicity. Some of these issues are not *unique* to ethnic minorities, but they do tend to be experienced more strongly or differently by them. Some of this group had what might be described as very resilient personalities as a result of their life experiences, such as fleeing the war in Poland or moving from Pakistan to an area where there are few Muslims and having to learn a new language and cope with racism.

**Access to advice and information:** understanding the system and knowing where to start can be even more challenging for members of this group; examples included: not being aware of Attendance Allowance, or not being told about voluntary organisations such as the Alzheimer's Society by medical professionals. One woman explained of her peers:

*"Some don't have the language, but more especially the confidence to push for things."*

We heard that cuts to specialist third sector services, such as the closure of the community advice centre for Cardiff's Somalian population, were impacting particularly hard on the older members of this community, who often speak little English, do not know the system as well as younger generations and experience a number of physical barriers travelling to and accessing generic services.

Older BME people tend to depend on their children and grand-children for advice and information. This approach is risky, since they rarely have sufficient expertise to provide accurate advice.

**Finances and tenure:** We know from previous literature (Care & Repair England 2010) that levels of owner occupation are particularly high amongst older people from some ethnic minority groups and that there is a high incidence of low income home ownership amongst black older people. Although the number of BME older people who completed a demographic form in our study is small, it is interesting to note that seven either owned their homes outright or rented them privately and that the majority of BME interviewees described their finances as 'just about managing'. Most were dependent on public transport and several told us they were just above the threshold for Pension Credit. One of these – a 70 year old semi-retired nurse who is caring for her older husband who has dementia - told us that she does agency work twice a week to supplement her small pension.

The Somalian older men we interviewed had received good benefits advice from the support worker at the sheltered scheme where they either lived or visited: some were in receipt of Attendance Allowance. However, an added pressure on the finances of this group was that they are trying to support family back in Somalia from their small private seamen's pensions.

The Polish participants (of our previous Joseph Rowntree Foundation study – see page 12 for details of this) were self-funders living in a Polish retirement village: they had all planned ahead and saved to move to the scheme and several had spent a lot of their own money making adaptations to their flats and buying mobility equipment. All were clearly proud of their continuing financial independence and the fact that they did not receive benefits:

*"I don't have any assistance except what everyone gets like free medicines."*

One BME couple described how they had been put off trying to access Social Services because the financial forms had felt too intrusive.

**Privacy, dignity, culture and care:** Our conversations challenged the assumption that black and minority ethnic older people are always part of large families and communities which 'look after their own'. Whilst we met one 'sandwich carer', looking after both her disabled daughter and her elderly parents, we met another who did not have family and seemed quite isolated, as a result of a combination of ethnicity and religion and years spent caring for her now deceased husband:

*"I have no family except one niece in Birmingham."*



Both of the carers in this group told us that the person they cared for would not accept outside help with personal care, because of privacy and dignity. The older Muslim men we interviewed explained that they would ideally like to receive personal care from younger men from their own community.

Although those living in the Polish scheme described close relationships with and regular visits from their families, several people told us that they did not want to 'spoil their children's lives' by being dependent on them for care and help.

**Links to ethnic community:** We met people either through a lunch group or a specialist housing scheme for older BME people and all emphasised the value of these settings in providing mutual support, safety and opportunities to mix with people who shared your culture and language. The mosque was also a key 'hub' for those who are Muslim, providing structure, meaning and regular contact with members of the local community, including a mix of ages. However, the mosque does not provide practical support or non-religious advice and information.

All of the Polish group told us they had moved to the scheme to be safe, to live in more suitable housing (which would allow them to live without depending too much on either family or state) and to be part of a community: most told us there had been few Polish people in their previous neighbourhoods.

One Asian woman told us how much she valued being able to go to the ethnic food shops in her local area and select her own vegetables: this brought social contact and familiarity as well as access to ethnic foods – things that could not be replaced by online shopping or someone else doing the shopping for her.

We visited Red Sea House – a sheltered housing scheme set up by Taff Housing Association to meet the housing and support needs of retired Somali seaman in Cardiff. The scheme has become a well-used and valued hub for the wider community and we heard of a high degree of mutual support within it.

However, this community of older people is very isolated from what they described as the 'outside world'. They rarely have opportunities to get out of the immediate vicinity (especially since a third sector organisation which used to take them by minibus to a local leisure centre has lost its funding) and told us they felt like a 'forgotten community':

*'When it comes to election time, government officials all come here wanting photo opportunities and making allsorts of promises – but, once they are in power, we never see them again'.*

Arranging for an interpreter to accompany them to health or other appointments can add complexity and delay and, although this group had heard of Social Services, they were unclear of their entitlements and how to access them.

## Chapter 5. Services: Perceptions and Journeys

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In this section, we present what older people and their supporters told us about their experiences and perceptions of services. By 'services', we mean statutory social care and health services and voluntary sector agencies, including information and advice providers.

We consider how people find out about or get involved with these services, and what keeps them from needing (or getting) help from statutory services. We consider the journeys which some people take through – or on the margins of – formal services through individuals' stories and reflect on the wider learning from these. We were particularly interested in how people's perceptions of social services might put them off seeking early help in ways which might promote their longer term independence and well-being and make them less likely to need help in a crisis.

This chapter makes sobering reading for those who run services; yet it is clear that the voices of the older people we spoke to confirm both the need for the Social Services and Wellbeing Act and the direction of travel it sets. However, these experiences and perceptions highlight the extent of the challenge and the depth of the cultural and organisational change required to implement the Act successfully.

Taken collectively, older people's voices paint a picture of how the health and social care system can look from the outside: how difficult it can be to understand who does what, what you are entitled to and how you can access it. Older people often described the professionals they encountered – with some notable exceptions – as seeming to see them through the lens of their specialism, and sometimes overlooking issues which fell outside of their remit. These findings confirm the importance of the Act's aim to take information, advice and assistance (previously only available through formal social services processes) directly to the citizen, so avoiding complex assessment processes and eligibility testing.

### 5.1. Perceptions and experiences of Social Services

Those we spoke to were **not** currently in receipt of Social Services, however, 33 of our participants told us they had been *assessed* by social services. 15 of this group provide care or support to another adult due to ill-health or disability, though we do not know whether they received the assessment as a carer or someone who might need care.

Some of those we spoke to had tried to access services or had received time limited support following an operation, illness or accident. Some people's experiences of support on discharge from hospital had been positive. For example, one carer explained that the "*OT reablement team were superb*" when her mother was discharged from hospital following a fall. She explained that, as a result "*she started to get her confidence back – they got her walking again*".

Although the majority of those we spoke to had limited direct personal experience of Social Services, we were struck by the extent to which people's *perceptions* of Social Services were shaped by hearsay from their friends and relatives, especially where this had involved negative experiences, and by the media. Not only can the news about bad experiences spread widely; but the impact of them can also last for a long time: in an extreme example of this, one man was determined not to ask for help from the state because his mother's application for a grant for shoes for him when he was a child had been rejected! Others had been turned down for one service (such as a disabled parking badge) and said that this had made them determined not to ask for anything else.

One man we spoke to described feeling 'dread' at the prospect of having to approach Social Services for help because of the negative stories he had heard about poor and very short domiciliary care visits.

*"You are filled with dread, because unless you feel that you can get the sort of help that you perceive that you should get, you'd rather not have it if it's going to be done in a haphazard way. And for that reason, it fills me with dread."*

Others did not feel that Social Services were, or would be, relevant to them. Sometimes this was a result of pride (it was 'not for us'; it was for 'the others' – people who were poorer, sicker, younger, older or less willing and able to be responsible for themselves).

*"I've never felt I needed Social Services – they're for people in worse circumstances than us, and I've no money worries."*

A significant number of people did not seem to understand what role Social Services might play in supporting older people and their carers: some people looked totally blank or seemed to be confusing 'Social Services' with 'Social Security'. For others, the use of jargon made it very difficult to fathom out what – if anything – they might be entitled to or what this might involve:

*"Someone said I could get either a carer assessment for me – I don't understand what that is - or an assessment for dad."*

We heard that some older people fear letting statutory agencies into their lives because they worry that they will lose control and independence; that they will be forced to go into a care home, or that they will be evicted from their home. This seemed to be particularly prevalent within longstanding Welsh-speaking communities in the North and West of the country, though it was certainly not restricted to them. For some, this fear is also driven by shame and a desire to remain private at all costs: we spoke to an outreach worker who was in contact with a lot of isolated older people who are adamant they do not want the neighbours to see support workers or professionals coming to their homes.

*"A lot of older people round here [a small town in a rural area] don't want to get involved with services or ask for help because they are worried they will be recorded or registered – that others will find out that they are not coping."*

### **'Careful planners' and self-funders**

At the other end of the spectrum, we met older people and carers who might be described as 'careful planners', who said they were just about coping now but were keen to get 'into the system' to reassure themselves about what might be available further down the line and to make sure agencies were aware of their existence should anything go wrong. This was felt to be a particular issue for (potential) self-funders who often worried more about whether and how they would be able to find and pay for help and felt there was less support to help them access this. One man, who was caring for his wife who had dementia, told us:

*"When I contacted our social services I said 'we're just about managing but if anything happened to me – I'm 85 – could you arrange a carer's assessment so that you would know about us in case of an emergency? And we'd be self-funding ...'. They just asked me a series of questions: 'Can she dress herself?' And so on ... I'm trying to think ahead! They just said 'You don't have any needs' and I was left with the feeling of being a boat on a choppy sea with no-one to say 'There's land over there'. This was just a telephone conversation. I haven't pursued it but someone from the Alzheimer's Society will now refer us. I have the strong feeling that I was brushed off because we're self-funding."*

Participants at one of our focus groups said that they were also concerned about whether owner occupiers could access any help:

*"There is this assumption that, if you own your own home you can pay for everything. Well I have downsized into a little terrace but I am asset rich and cash poor...."*

*"Yes, I used to own my own home but, before I had to sell the bungalow – when I owned my own home, I got refused help from the council, from all sorts of places, so I agree."*

*"If you own your own home, it is almost as if people don't know you are there.... Apart perhaps from the census."*

## **Specific themes emerging from criticism of Social Services**

Older people's misgivings about Social Services often captured very accurately those shortcomings of the system which the Act is seeking to redress. One way in which Social Services differs significantly from many other public services is that it is not a whole population service, but one which is targeted at certain groups which are deemed to be vulnerable. It is not free at the point of entry (like the NHS) but access is means-tested. The implication of this is that 'service users' can be stigmatised and that a significant part of the system focuses on gatekeeping or assessing for eligibility – a point which often creates frustration and confusion for those who are on the edges of services.

### **Bureaucracy**

Some of those we spoke to expressed their frustration with the bureaucracy of statutory agencies: the waiting times, the eligibility criteria, and the inflexibility.

One woman told us she had asked for some social support for her husband; she wanted someone else to take him out occasionally. She was offered a direct payment but she told us that she was unable to recruit a suitable carer. Another said they struggled to complete carers' forms and had been passed around a number of people when they rang up to get some support.

One very frail couple told us that what they really wanted was meals on wheels, but that their council no longer provide this service. However, the council which operates up the road does: a point which they found frustrating and confusing. Similarly, we heard that basic preventative measures (such as alarm pendants and grab rails) were hard to access in some areas, and that there were varying charges and referral mechanisms in different areas.

The initial wait for an assessment was also mentioned by some people:

*"I don't understand why, when you ring SS – if you don't have a current social worker they put you through to a duty SW who writes everything down and it is 13 weeks before a SW or an OT comes to see you. Why does it take so long? You phone up because you need help there and then – you might be dead or things might have got a lot worse by the time they come out (I suppose sometimes things will have improved) but it just doesn't make sense as a way to run a system."*

## The assessment process

Many of those who had experienced, observed or heard about social care assessments had a number of criticisms of the process. Some felt that they were rushed or that professionals asked the wrong questions (or asked them in a way that meant people had to 'admit' their limitations). We heard a number of examples in which this approach had led to people not receiving the support that they really needed.

*"We met with social services and my mother-in-law then answered the questions that were being asked: 'Are you ok?', 'Yes', 'Can you manage?', 'Yes, no problems at all', because people from that era are that proud they don't want anyone to know that they can't do this and that."*

Others felt that professionals did not listen properly and were either overly keen to slot them into what was available or tell them what they should do, rather than take the time to understand what they actually needed and wanted. A woman who used a wheelchair summarised this point very well:

*"I want someone to come and listen to me and understand the challenges I face and work out with me what I need to go about my day-to-day life, not just give me what they've got in the storecupboard!"*

## What is on offer is not the right kind of help

A recurring theme from carers in particular was that the type of services that might be available to their family were not useful to them.

One woman, who cares for her elderly mother explained:

*"Well they probably could organise for someone to come and put her to bed but they would more than likely turn up at 8pm when she is in the middle of watching East Enders and she doesn't want to go to bed then. And then if she has a bad night I might have been up 3 or 4 times with her in the night and she'll lie in late so, again, we don't want someone turning up at 7am to get her up. So I appreciate that the service is there, but it isn't actually any use to us."*

Meanwhile, she was really keen to find someone who could come and sit with her mother for a day every so often, so that she could either go and sort out her mother's home (which was sitting empty and full of her possessions) or go to see her grandchildren who lived at a distance.

A recurring theme from our focus group with older Somalian men was that they needed a bit of help with domestic chores in order to help them remain independent but that they could not afford to buy in help.

Despite negative perceptions, many recognised that these services were under huge pressure due to cuts to local authority funding. People often sympathised with social workers, who were typically portrayed as nice people, trying to do a tough job in very difficult circumstances. We heard some examples of older people and carers effectively self-rationing and not asking for help from Social Services because they assumed none would be available, or that there are others who needed it more.

Members of one over 50s forum suggested:

*"It would be good if Social Services came here and explained some of the problems they are facing more openly – you know with the cuts, the challenges care workers are up against, then we could hear each other and do some joint problem solving – otherwise it all ends up being very defensive."*

### **Fred and Mary's Story: Part 2**

On page 20, we introduced Fred and Mary – a couple in their late eighties, caring for each other, despite the fact that both of them have significant health challenges.

Fred and Mary currently have no support from statutory services or voluntary agencies. They had six weeks' input from the frailty team after Fred was in hospital with pneumonia. At the end of this:

*"The man in charge said 'if you need us for anything ...' but I haven't bothered them ... but someone said we should be having it, he's got to go to hospital next week for treatment for his prostate."*

Mary explained that *"Social services gave me a list of lunch clubs, but I haven't had time to find out about them ..."* (though, given her visual impairment, it would be hard for her to read and research these without some support).

Mary and Fred did an equity release plan some time ago. This should, in theory, provide them with a reasonable income, but it would make it very difficult for them to move to a more suitable property (like an extra care housing scheme, which might work well for them).

Mary is very worried that Fred will lose his driving licence, and she has no idea what they will do then: *"When my husband is well enough we use the car to go shopping once a week, but he's had a slight stroke and his memory is going ..."*



Fred and Mary have experienced a number of the challenges from our 'anatomy of crisis' model: they both have significant health problems which are likely to deteriorate, they are isolated in terms of an absence of family and friends to draw on for help and assistance, and the possibility that Fred may lose his driving licence which will severely limit their ability to get out and remain independent.

However, so far they have not needed formal Social Services assistance because of:

- Being each other's carers;
- Having used an equity release plan to provide themselves with additional income.
- Having the tenacity to remain living independently.

The key missed opportunity is that, when Social Services did have some contact with Fred and Mary, the option for them to move to a more suitable property and supportive environment was missed, even though this would be difficult in the context of their equity release plan, which may ultimately result in them requiring assistance from Social Services.

## **5.2. Perceptions and experiences of the National Health Service**

We were struck that, in contrast to Social Services, the NHS was often held in high esteem, even when services were really quite poor. This may be a hangover from the history of this institution; with its links to Bevan and the post-war era which was so formative for this cohort. It may also link to our tendency to accept the legitimacy of medical authority (which may be particularly strong for this generation), and the fact that, unlike social care, the NHS is both universal and free at the point of access.

We heard of very varied levels of contact with General Practitioners (GP): some people were offered an annual health check; others avoided their GP altogether.

*"I think as long as you don't bother them, they don't bother you.....If they sent me a letter and offered me a check-up every so often it would set your mind at rest."*

A common complaint was the length of time needed to wait for an initial appointment with your GP: some people had been sent straight from their appointment to hospital. Others were concerned that the appointment slots are too short, especially for people who have multiple conditions. People living in remote villages greatly valued chemists who delivered repeat prescriptions; though apparently this service is not available in many places. In another area, older people praised the Falls Prevention scheme, which ran Tai Chi and swimming classes.

Some people described the fear and shame which meant they had put off going to see their GP about the symptoms of dementia. An Asian woman who was caring for her father who drank alcohol quite heavily also described her fear about the reaction of doctors and her own community to this.

One carer told us about the substantial delays she had experienced getting seen at Accident & Emergency following her mother's and mother-in-law's various falls: even when they were in an ambulance! The restructuring of hospital services was a cause for concern. People told us that they now needed to go much further afield to attend out-patient appointments and visit partners and friends who were in hospital. This seemed to be a particular problem in West Wales, but was also felt keenly in North and East Wales too.

Several carers complained that their loved ones were not challenged at all to maintain their independence while in hospital. For example, one man was put in incontinence pads unnecessarily so he then had to be re-educated to use the toilet on discharge from hospital.

Some people felt they had experienced age discrimination from medics; usually around being ignored or not taken seriously:

*"I have had a bad experience of doctors ignoring me and just talking to my daughter ... it happened with my husband too."*

Some people had been left in positions that it is hard to imagine a younger person being left in. For example, one woman, who has severe arthritis in both her feet and hands, told us that she had been without shoes which she could put on herself and wear comfortably for over a year. She explained that she is in constant pain walking. A man with dementia waited nine months to get an initial audiology appointment, despite the fact that his hearing was deteriorating rapidly.

We got the impression that the pathways for care and the linkages to Social Services, Occupational Therapy and information and advice tended to be better when there was a clear medical event, like a hip operation, rather than for ongoing long term conditions. However, our sample is small and there were exceptions, for example we heard some very positive experiences of the pathways for cancer.

*"When my wife was diagnosed with cancer a lady came who was associated to the Social Services and she came along and discussed it very thoroughly with us and worked out all of the help and assistance that we would need and worked out a programme of who was going to come in, Care & Repair and so on. And that was triggered by Ward 8 in the hospital."*

Others had less positive experiences where jargon and poor communication meant that opportunities to access other pathways had been missed or delayed. One carer told us:

*"When he was in hospital this time the doctor talked about palliative care but she didn't explain what that was, even when I asked, but they said he'd have to stay in hospital another week to have an assessment and she told him that after she had said he could go home! So he didn't want to stay – this was three weeks ago and she said they'd write to the GP and the GP would be in touch ... but we haven't heard anything since.."*

Palliative care is primarily concerned with the management of pain, which – as we heard in Chapter 2 - is a key determinant of well-being for older people. Although our sample is small, our findings do suggest that some of the health issues which can impact most on older people's day-to-day well-being, such as pain, continence and foot care risk getting overlooked by health systems.

### **Brenda's story**

Brenda has been living on her own for the past few years since her husband died. The couple had moved a decade ago from a 3-bed house with a big garden in a commuter village with poor public transport. Brenda could not drive though her husband did .....

*"We felt cut off there even then.....On purpose we were looking to the future – we didn't want to be stuck, so we downsized to a ground-floor flat..... with buses around the corner".*

Brenda's son lives nearby and her daughter phones every night. They are both busy with work ("I try not to be at them all the time") but "they've helped me more since my husband died..... I don't know what I'd have done without them".

Earlier this year, Brenda was ill for five months: "I was absolutely exhausted all the time..... I'd never been ill in my life except for colds and it knocked me for six.....I lost three stone but the worse thing was the muscle weakness. I couldn't get up out of a chair and I was afraid to kneel down in case I couldn't get up – and there was the double vision ..."

Her doctor thought these might be a delayed reaction to the shock of losing her husband but eventually he decided to test for thyroid and diagnosed her with Grave's disease.

"Now I feel all right in myself..... As soon as I took the medicine it calmed down". However she told us that she still feels very unsteady on her feet due to ongoing problems with her vision.

Brenda recognises that Grave's can be triggered by stress. She accepts that she hadn't been coping but she felt she had got through that stage. *"I thought I'd go to pieces but I surprised myself – I felt so calm, but I was in a bubble, a strange feeling.....My faith was important... I feel I've come through a tunnel – life is different – I've got used to living on my own'.*

Brenda told us that the people from the church where she used to be a sidesperson have been 'very supportive' through this period. She had had some contact with Age Cymru over her husband's disability pension and with Care and Repair for minor electrical works. She can use the internet for basic tasks like sending emails.

*"I suppose I might have gone to Social Services if I'd been on my own without the children ...I've never felt I needed Social Services – they're for people in worse circumstances than us, and I've no money worries. It's very difficult to ask for help when you're used to doing things."*

Brenda is back to being active again. *"A good day is to get out and about – if you rest you rust! I go to a keep-fit on a Monday, a craft class on a Wednesday, then Mothers Union...."*

## Commentary

Brenda experienced a number of the challenges from our 'anatomy of crisis' model at the same time: her health suddenly deteriorated and she was recently bereaved, leading to risk of loneliness, falls and loss of confidence.

However, she did not need to use formal social services because of:

- Careful planning: moving house made it much easier to remain independent after her husband's death and during her illness;
- Supportive networks of friends; and children who live relatively nearby (but with whom she manages relationships sensitively);
- A resilient personality, bolstered by religious belief;
- Familiarity with voluntary organisations and an ability to use the internet;
- Diagnosis and management of her health condition; and
- Being comfortably off so able to source own care if needed.

But there were still some missed opportunities that could have led her to need more statutory support:

- Delays in diagnosis and treatment left her at risk of falls (despite having supportive children, they may not have been able to look after her after a fall due to their own working lives) and
- Exhaustion which severely limited her social contact for many months and could have led to depression.

### 5.3. Perceptions and experiences of the voluntary sector

Many people told us that they had found the voluntary sector – organisations like Age Cymru, Care & Repair or The Alzheimer’s Society - more approachable than Social Services. For example, when we asked one group whether they had needed to go to the council or Social Services for information, they replied:

*"I think we would all go to Age Concern and tell them."*

*"Yes, Age Concern – that’s our Social Services – well mine anyway."*

[So you are more likely to go to an organisation like Age Cymru?]

*"Yes [most]. Yes, definitely."*

[Why?]

*"Well they can speak for all of us, can’t they...They are more helpful."*

*"You get results. You get things done."*

Another person told us that, if you call the Council for advice and information,

*"you get passed from one department to another one until you get fed up to the teeth, don’t get an answer so you think ‘blow this’, so you ring up Age Cymru and they give you an answer straight away."*

However, we heard some examples of voluntary organisations failing to communicate with each other, duplicating services, or missing opportunities for prevention. Yet, for many older people and their carers, such organisations often act as a gatekeeper for a whole range of services, signposting, advocating and arranging claims for previously un-claimed Pension Credit or Attendance Allowance. This is clearly illustrated here in Gwen’s story.

## Gwen's story

Gwen is in her late 70s and has COPD (Chronic Obstructive Pulmonary Disease) and very bad arthritis. She really needs a knee replacement but the combination of the COPD and being overweight means that it would not be safe to operate. Her COPD is now so bad that she is permanently on oxygen.

Gwen's son has recently bought her a second hand mobility scooter which can carry her oxygen cylinders and will enable her to go by herself to the supermarket. However, she is currently waiting for a ramp and alterations to her front door so that she can get in and out of the house in the scooter.

Gwen gets some support from her son, who visits every week and also drops her off at Bingo:

*"Whatever I ask, he'll do it, but he works hard and at the weekend it's football Saturday and being with his partner Sunday"*

Neighbours are also very supportive – one man has done the garden for her and is an electrician. He noticed that her oxygen, nebuliser and other equipment were on lots of extension cables and adapters (which could create a trip hazard or fire risk), so he is going to come and put in some more sockets for her. Neighbours also bring her Christmas dinner and she trusts one neighbour to take her cash card and do occasional errands for her.

Gwen first came across an agency (she cannot remember whether it was Age Cymru or Care & Repair) through their office in the town centre. When one of the agencies rang her at home, they asked what the noise was. She explained it was her oxygen cylinders and they asked if she received Attendance Allowance. They immediately helped her to get the higher rate (£80 per week):

*"No-one tells you anything – I've never heard of any of these allowances for disability – this girl who came to do the claim for me, she knows all about it ...."*

She uses the extra money for taxis to town and the doctors (it is hard getting on the bus with the oxygen) and to pay someone she knows to do cleaning and shopping for her.

Care & Repair arranged for:

- new central heating (her old back boiler needed £300 to repair and she did not have the money);
- a stairlift (after they observed her going up the stairs and unable to breathe – she had been like this for two years);
- a wet-room with a sit down shower; and
- a key safe.

She had received too much from Care & Repair to get funding for the ramp, but they have helped her to get a full grant for this from SSAFFA (The Armed Forces Charity, as her husband had done National Service).

Gwen told many jokes about herself and her life throughout the interview, but she explained that apart from a weekly shop, her weekly trip to Bingo is the only time she really gets out and sees other people:

*"There's days when I'm on my own for hours, I'm bored of my own company... Sometimes I'm inside dying."*

Gwen told us that she is determined to continue living and die at home. She sometimes admits that she lies to others about her health because she does not want to be forced into a care home. She also told us that she used to go on a regular holiday, but that she has had to stop this now, due to the logistical problems of the oxygen.

*"Every year I went to Turkey on my own, the same hotel, they're like a family to me. I thought either don't go and sit at home on your own, or go and make new friends..... This year I had to cancel it when I had pneumonia. The trouble now is getting the oxygen, you can't take it with you and I'd need it at the airport and then on the plane and then in the taxi to the hotel .. in the end I had to give up but I'd like to go once more if I could ..."*

## Commentary

Gwen's situation contains a number of risks linked to our 'anatomy of crisis' model:

- Her deteriorating health;
- Depends on neighbours, a son who works away a lot, and friends (but linked to being able to go out to Bingo and the town centre) for support;
- Loneliness and isolation at times;
- Risk of loss of confidence

However, so far, she has not needed anything from social care services because of:

- Attendance Allowance which has enabled her to self-fund some additional support (but she may need more care in future and is on a very low income);
- Help from Care & Repair: her home will soon have all possible adaptations – but may not be enough if her health deteriorates further, especially given that she lives alone;
- Support networks (but, as above – there are risks and questions about how far these could go); and
- A very resilient personality.

However, there were some missed opportunities (and near misses!) which could have led to her needing more statutory support. All of the following risks were eventually picked up (but by chance), and should ideally have been identified through the health service at a much earlier stage, given the seriousness of her health conditions:

- Need for adaptations (risk of falls or needing long term domiciliary care to bathe and get up and downstairs);
- Benefits check (had not been claiming Attendance Allowance until chance encounter with voluntary agency in the town centre);
- Risk of fire and trips from electric wiring for nebuliser picked up by neighbour (who happens to be an electrician).

#### **5.4. Access to information and advice**

Being able to get hold of accurate information about a range of topics – from benefits, to housing, to social activities – was felt to be absolutely essential to enable older people and their carers to remain independent and, crucially, to plan ahead.

However, we heard how many people did not know where to start or even what they were looking for; even those who were highly motivated, articulate and able to access a computer described almost farcical attempts to find information. Others do not have the language, the confidence or the time to push: one older European woman explained, “*We are the people who do not shout*”.

The idea of one designated phone line was popular – in many areas, we heard how the phone numbers always seemed to be changing.



Information was not always accessible: some people felt angry about the increasing trend for only making information available online; others felt overloaded with leaflets. As we have heard, Mary – who has a visual impairment – was given a printed list of lunch clubs and offered no further assistance. Sometimes information was given to one family member, but then not passed on – this was sometimes because the dynamics of caring relationships were overlooked. For example, one man, whose wife has limited mobility, was taken into hospital for an operation. His wife thinks that *he* may have been told about the Red Cross shopping service, but (perhaps because he refuses to wear his hearing aid), he either did not hear this or did not think to pass this onto her. As a result, she spent a week stuck in the house alone with no shopping, dependent on neighbours bringing around occasional meals. It is possible that services did not see him as a ‘carer’ for her and therefore did not recognise the impact of his hospitalisation on her.

Friends and chance encounters were often a key source of information. One British Asian woman explained that:

*"I spoke to one of my friends and she told me about the Alzheimer's Society and I got in touch with them. I had no idea that they existed – the consultant never told me, the GP never told me."*

Where people were members of social groups and clubs, it was clear that these were also an important and trusted source of information.

Gwen's story is interesting in relation to information and advice: once Gwen had a known contact at Care & Repair, who took a proactive and personalised approach, a number of opportunities – for Attendance Allowance, and for adaptations – opened up.

## Chapter 6. What is the learning for a whole system approach to 'prevention'?

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### 6.1. Introduction

In this section, we consider what the evidence from the voices of older people and carers means in terms of a 'whole system' approach to prevention. We also link back to key findings from our evidence review.

We set this in the current policy and legislative context that is strongly focussed on promoting well-being and 'preventative' approaches to assisting older people and other citizens.

This poses a series of fundamental questions:

- What is meant by 'prevention'?
- What is this independence that we are trying to 'restore'?
- What do concepts such as 'prevention' and 'independence' mean to older people?
- What are the implications for Government, policy makers, practitioners and other organisations that seek to assist older citizens?
- What is the nature of the relationship required between older citizens and their carers, and professional organisations and their systems and processes?
- What are the levers for change? What does change mean in practice?

We draw on the evidence from older people and carers to seek to address these questions.

### 6.2. Context

Wales has an ambition to take a world class approach to creating a society where older people can lead a good life and are treated as valued and equal citizens; i.e. making Wales a great place to grow old (Strategy for Older People in Wales 2013-2023).

This research provides evidence from the perspectives of older citizens and carers about what might be effective in helping to achieve this ambition.

The wider context for this research is a set of policy and legislative changes that are designed to make a positive impact on the lives of older people living in Wales. These in particular include Ageing Well in Wales, 2014-19 which sets out the broad objectives for a preventative approach:

*"...the Programme will focus on preventative actions and interventions. Preventing frailty and preparing older people to sustain their independence will, in turn, support them to take ownership of their health and well-being."*

The recently published (November 2015 – draft) *National Outcomes Framework for people who need care and support and carers who need support* describes national well-being outcomes for these groups of the population. The key objectives include:

- Providing the opportunity for people to have a greater voice and more control over their lives and enable them to make informed decisions that engage them in improving their own well-being;
- Working in partnership to build on people's strengths and abilities to enable them to maintain an appropriate level of independence with the appropriate level of care and support, where this is required;
- A shift in service provision to a focus on well-being outcomes through working with people and carers to understand what matters to them; and
- Shining a spotlight on what needs to be done to improve people's well-being rather than focussing on the processes involved in delivering social services.

The national well-being outcomes include:

- *I can learn and develop to my full potential;*
- *I contribute and enjoy safe and healthy relationships;*
- *I manage and make a contribution to my community;*
- *I am healthy and active and do things to keep myself healthy,*

These clearly resonate with what older people have said to us, though it is important to remember that the people we spoke to were not in the main receiving help from Social Services. Sometimes this was through choice, sometimes because services were not available, and sometimes because they did not need any additional help or support. However, many of them had health problems or disabilities, and were providing and/or receiving care and support from neighbours, friends and self-funded help.

The theme of well-being is at the centre of recent and current policy and legislation in relation to social services in Wales. However, *Ageing Well in Wales* notes that the concept of well-being is not yet sufficiently understood and reflected in the planning, development and everyday delivery of public services. There is often a focus on the issues of health and social care:

*"but...the voices of older people show that well-being is much more broadly defined, including leisure, learning, work, housing, transport, community facilities and the nature and quality of relationships are all essential components of the well-being of older people".*

The Social Services and Well-Being (Wales) Act 2014 reframes the responsibilities of local authorities and their statutory partners in Wales. Key themes of the Act include:

- A focus on user voice and control. The evidence from our research is that older people said that having control over your life and what happens to you is at the core of being and remaining independent.
- It emphasises the promotion of well-being and the prevention or delay of the need for formal social and health interventions. Many older people we spoke with were keen to avoid the need for help from Social Services and many people had developed resilient approaches to maintaining their independence.
- It emphasises helping people to have the confidence and resources to help themselves. The ability to live your life without having to rely (too much) on other people was seen by older people as an important part of being and feeling independent.

### **6.3. Prevention and independence— the evidence of what this means to older people and carers**

'Prevention is not just about providing the same service in similar portions at an earlier stage, it is about equipping people with skills, coping techniques and circumstances to remain independent. It is a responsibility that extends well beyond Social Services'

*Roberts (2012)*

'Prevention' is not a word which older people would themselves use or understand in this way. It has tended to be defined in professional ways that emphasise service responses to the needs and requirements of older people. Any approach to 'prevention' and assisting older people to maintain their independence needs to be grounded in the lived experience, views and perspectives of older people and their carers.

Good 'outcomes' are understood as having a good life; they are not defined in terms of any types of 'services', although 'services' may be required and/or desired at times to support a good life.

Our evidence review identified a number of examples in which local authority Social Services were seeking to take 'community based' approaches to prevention. In these approaches, every interaction with a person focuses on whether or how their needs could be reduced or future crises prevented.

However, these approaches still remain grounded in professionally mediated views of what 'prevention' should mean and look like. A fresh approach to prevention will need to be based on what older people say matters to them and what being independent means to them:

Being able to get out and about when you want to;

(Not) having to rely (too much) on others;

Being able to move around in and maintain your own home;

Having control;

Feeling good about yourself;

Being connected to others;

Staying active; and

Being well and managing pain.

Equally important are the barriers which older people said can prevent them from maintaining their well-being:

- Transport – problems with getting access to private or public transport;
- Home environment – problems with accessibility, location, maintaining and heating a home, difficulties in being able to move home;
- Neighbourhood – lack of availability of local facilities; an absence of the sense of community safety (or the fear of crime); a lack of good relationships with others in the local community;
- Money; e.g. concern about the current and 'new' state pension level not being enough to meet basic needs;
- Information Technology (IT); an opportunity for some older people but for others a barrier due to lack of knowledge, skills and confidence; cost; and poor connectivity in some rural areas;
- Lack of awareness and confidence, which can often be a consequence of other factors such as health deterioration, carer breakdown, or a fall/accident.

## 6.4. What are the implications for Government, policy makers, practitioners and other organisations that seek to assist older citizens?

### Approach to 'prevention'

The notion of a 'whole system' approach to prevention focuses on how different elements of the public realm or 'state' can best be aligned and organised to help older people. A clear message from our research is that older people sometimes felt 'passed from pillar to post' in their dealings with services. We also heard many examples in which decisions in relation to one service (e.g. rejection for a blue parking badge) could have a knock-on effect (e.g. risk of falling).

Local authority Social Services have tended to focus prevention or 'early intervention' strategies to address specific priorities, e.g. a plan to reduce falls in order to seek to reduce hospital admissions. A whole system approach typically involves looking beyond more than one or two preventative or 'early intervention' strategies, for example considering the important role played by such services as libraries, community centres and transport. A recurring theme in our study (and one which has been explored in more detail by Auditor General for Wales (2015)) is that local authority cuts are reducing the availability of these types of services and facilities which form part of the 'whole system' that enables people to maintain well-being and independence.

In our evidence review, we identified a general consensus that taking a community based approach which builds on social capital and local assets is an essential component of a sustainable and progressive model of adult social care. However, at this stage, the evidence is of 'micro examples' rather than a 'whole system' approach to community based 'preventative' approaches grounded in the views and lived experiences of older citizens.

We heard from older people examples of 'missed' opportunities for prevention (see section 5), which suggest there is a need for a different type of whole system thinking.

However, it is also important to recognise that this is not simple and a top down approach is unlikely to be effective; some of the older people we spoke with are instinctively resistant and reluctant to accept help and assistance from formal social services. For example, we heard that some older people fear letting statutory agencies into their lives because they worry that they will lose choice, control and independence.

## Relationship between state and citizens

*Strategy for Older People in Wales 2013-2023* notes that real differences to older people's lives can only be made through a shared commitment across the statutory, private and voluntary sectors to shape services that are sensitive to their needs.

This research suggests that improving the well-being of older people needs to look beyond shaping services. Traditional prevention models have typically been service based approaches and interventions. However, a series of key themes emerge from our research that indicate a need for a clear change of emphasis.

At a macro level this can be understood as:

- Cultural change: how local authorities (Social Services in particular) and other public organisations view and relate to older people – as citizens rather than clients;
- A different form of partnership and collaboration: between and with older people, carers and their families;
- A new social contract: the nature of the relationship between people (older people in this case) and the state;
- Shifting the balance of power: where power does and should reside between older people, local communities and national and local government (and other bodies); a more personalised and co-produced approach to adult social services in which the main resources of interest are those held by the individual and the community rather than the state; and
- Redefining roles and responsibilities: between Social Services and other public agencies, voluntary sector organisations, community associations and older people.

This suggests the need for a new approach to thinking about and enabling 'prevention' which is about local authorities and their partners understanding:

- When to do nothing - in many cases older people are successfully maintaining their independence;
- When direct involvement and action is necessary, e.g. in the context of social care, how to do this in ways that remove or minimise the barriers faced by older people in achieving good outcomes; changing the nature of 'conversations' and interactions between older people and Social Services from 'needs' led to 'strengths based' approaches.
- How to support the informal community infrastructure which enables older people to effectively manage their own well-being (e.g. community groups which provide opportunities for socialising, offer practical help and information, etc);

- What forms of activity and investment local authorities and other public bodies can deliver or broker that help to 'shape' a preventative environment, e.g. access to transport, leisure facilities, promoting safe and secure places, widening housing options for older people.

## 6.6. What does change mean in practice? What are the levers for change?

Key conclusions for practice from our research in relation to prevention include:

- Opportunities to prevent crisis and promote independence are sometimes missed because workers are 'siloed' in their part of the system and may find it hard to focus on and respond to the whole person. We heard, for example, of health services not identifying trip hazards or failing to signpost to support organisations or for disability benefits.
- 'Prevention' tends to focus on the practical and physical – a grab rail or a pendant, which are clearly important; however the evidence gathered here suggests that there may not be enough focus on emotional, social and psychological elements of 'prevention', particularly in relation to carers, e.g. understanding and supporting people's relationships, helping them to plan and make decisions, to come to terms with changing capabilities and roles.
- The evidence suggests a need to turn the conversation about care and support into a more equal and positive transaction, which tunes into the person and what matters to them, rather than a series of questions which assume that people will 'admit' their limitations. This is vital if those older people who are currently resistant to the idea of asking for or accepting help from statutory agencies are to be persuaded to do so in a timely way.
- 'Prevention' tends to be seen in terms of services (and then often only social services). Our findings suggest that more could be done to understand and nurture the role of informal support in neighbourhoods and to ensure that this consideration is embedded in planning and commissioning.

The learning from this research suggests a number of 'levers' that might bring about positive change to improve and enhance well-being and personal resilience. These are summarised in the table below.



<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
<p>Devolving choice and control to citizens</p>	<p>This requires a much clearer statement of roles, responsibilities and expectations of the state in retirement – what can we reasonably expect? What do we need to take responsibility for ourselves (and on behalf of our family members)?</p>	<p>Many of the older people we spoke with said that being 'in control' was important to them; they valued being independent. The prospect of losing your independence tended to provoke great fear (chapter 2). This is an opportunity to 'reframe' the relationship between older people and the state/ local government.</p>
<p>Supporting and drawing on the role of community level organisations and facilities</p>	<p>These types of organisations and resources are an integral component of an individual's well-being. This emphasises the importance of protecting community facilities and infrastructure as far as possible; e.g. whilst it is recognised that local authority budgets are reducing, funding reductions for community resources such as libraries and public transport will have a negative impact on the well-being of some older people.</p>	<p>Older people said that the diminution and loss of community facilities and resources, particularly public transport and leisure facilities (chapter 4) has a direct negative impact on both maintaining independence and well-being.</p>

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
The centrality of having a good place to live	Effective and practical forms of support to assist people to stay in their own homes is essential (e.g. via Care and Repair type services). However, a wider range of housing options need to be available to older people who wish or need to move to a different type of housing or location to maintain their well-being and independence.	Older people were very clear that getting the home environment (chapter 4) right, whether in terms of staying put, fitting adaptations or moving on, is critically important in terms of having a positive sense of well-being.
Nurturing and fostering community based forms of 'natural' support and assistance.	This emphasises the importance of supporting and linking up with natural community connectors and hubs; this is particularly critical to ensuring that key information and advice messages get to people. Other approaches may involve promoting and facilitating simple structures for mobilising peer support within neighbourhoods (e.g. Circle, TimeBanks) so people do not have to ask or offer help directly to or from others.	The centrality of relationships (chapter 3) in maintaining well-being was important to the majority of older people. When this is reflected in the range of connections and relationships within a neighbourhood it has a particularly powerful positive impact for older people's well-being (chapter 4).

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
The experience and perception of Social Services	A radical culture change within Social Services, which involves having a very different conversation with people; one which is strengths-based, which focuses on what really matters to people and how they can best be supported to achieve and sustain this; not one which only has one or two 'answers' and wastes a lot of time rationing access to them. This needs to be an approach that works effectively with families, couples, networks of people (e.g. through 'Circles of Support') in order to support the whole system and not just the individual.	Some of the older people we spoke with did not feel that Social Services were, or would be, relevant to them. Others had a highly negative perceptions of Social Services (chapter 5). The implementation of the Act by local authority Social Services presents an opportunity to reset this perception.

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
<p>Closer working between Social Services, health and other public services.</p>	<p>This would include strengthening partnerships with health, housing, police and other public bodies; this is partly about making sure that these professionals are trained to identify and respond to opportunities for prevention but it might also involve finding a way to reward and incentivise this approach. This will require putting self-interest aside, really listening and not over-focusing on structure. This reinforces the intention of the Act in bringing about real integration between Social Services and Health.</p>	<p>Older people’s voices paint a picture of how the health and social care system can look from the outside and how this can often be perceived and seen negatively (chapter 5). The intention of the Act to bring about genuine integration of social and health services reflects the aspirations of older people we spoke with.</p>

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
Simplifying and making transparent 'pathways' to formal help.	The systems that have developed are extremely complex: the menu of services, who is eligible for them and how to access them varies from area to area. Systems to support people who need information and advice, brokerage and advocacy to help them work out what they are entitled to and how to 'get into the system' need to work in a way that is most efficient for all concerned. Offering proactive holistic checks (benefits, local groups and services, housing options, etc.) may be one way of doing this, possibly through the voluntary sector and/or workers based in GP's surgeries. Offering pendant/ care line services free to those living alone was one idea which was suggested in the research.	Being able to get hold of accurate information (chapter 5) about a range of topics – from benefits, to housing, to social activities – was felt to be absolutely essential to enable older people and their carers to remain independent and, crucially, to plan ahead. To encourage more older people to become 'careful planners' (chapter 5) requires the provision of high quality information and advice.

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
The role of voluntary sector organisations	There is potential to develop and extend the role of voluntary organisations (which already often have older people’s trust) in promoting the well-being and independence of older people; for example, this might include proactive regular well-being checks, undertaking the ‘assessment’ and the information and advice functions on behalf of local authorities.	Most older people had a positive impression of and many had had a positive experience of interacting with voluntary sector organisations, with some people describing voluntary organisations as effectively being their ‘social services’ (chapter 5). Working with the voluntary sector in this way may help Social Services to avoid some of the current negative perceptions e.g. in relation to assessment processes.

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
Developing local community based partnerships	Partly in response to public sector funding constraints, it will be important to have a range of small scale but implementable strategies appropriate to a particular town or community where the investment from formal services might be to build on and foster community based forms of support e.g. a good neighbour scheme might reduce loneliness; communities might become dementia friendly to promote the safety and inclusion of older people living with dementia.	The importance of being connected to others and feeling good about yourself (chapter 2) was identified as being important for maintaining well-being. The approaches to prevention adopted by Social Services and their partners need to reflect these 'soft' factors as part of facilitating and fostering local partnerships with older people.

<b>Lever for change</b>	<b>What it means</b>	<b>Relationship to what older people and carers said</b>
Supporting Carers	<p>Carers play a vital role in supporting older people to keep well, stay at home and minimise the need for time in hospital or care homes. Many carers are themselves older, perhaps with their own health problems. Carers often have to juggle competing demands, including looking after themselves, their other caring roles and paid work. It is important that their role is acknowledged and supported by statutory agencies; in many cases they are experts by experience. The support that is offered to carers needs to be timely, flexible and responsive, including respite breaks, tailored information and advice, practical help and emotional support. Voluntary agencies and local networks have an important role to play.</p>	<p>Carers talked about the strain of being tied to the home (especially spouses of people with dementia). Even if services were offered, they did not fit their lifestyles and needs (see Chapter 5 on the wrong kind of help).. The impact of changed roles and relationships, especially for couples (see Chapter 3) meant that carers needed emotional support and time to get out and maintain their own interests and friendships.</p>



## Appendix 1: Methodology

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### Planning the fieldwork

Phase 1 of this project involved a review of the existing research evidence (see Blood, Copeman & Pannell 2015). We then met with the SSIA Steering Group to prioritise the research questions which had emerged from this review and to identify five pilot sites across Wales. The Group selected the following geographical areas, with the aim of covering urban and rural areas across North, South, East, West and Central Wales:

- Ceredigion, Pembrokeshire, Carmarthenshire and Powys
- Gwynedd and Anglesey
- Monmouthshire
- Newport
- Wrexham and Flintshire.

We also conducted a focus group in Cardiff with a group of Somali older people. We wrote a topic guide and shared this with the Steering Group. For group discussions, we decided to begin sessions by asking people what a 'good day' involved for them, then exploring who they would spend it with, what makes it 'good' and what (if anything) gets in the way of them having more 'good' days.

We developed a menu of eight questions (with two supplementary questions) to be drawn from and used as prompts. We did not ask all the questions of each person we spoke to, since we wanted older people to lead the conversation and tell their stories as naturally as possible. The topic guide is included in Appendix 3.

### Recruiting participants

We were set the target of speaking to at least:

- 100 older people (ideally aged 75 and over) who were starting to experience barriers in their lives, but were not receiving statutory social care services; and
- 30 people caring for older people.

We identified local authority contacts of both the Steering Group and the Research Team from each of the fieldwork sites (in some cases, this involved more than one contact where sites covered more than more authority).

We produced a flyer for older people and carers and an information sheet for professional 'gatekeepers', both in local authorities and in voluntary sector organisations. We used local authority introductions and/or directories of services to identify the best ways of reaching our target groups in each of the areas, during the project timescales. This flexible approach resulted in a range of different approaches in each area, including:

- Bespoke focus groups (or mini-focus groups including two or three people), organised for us by local authority older people's development workers/other Officers, Age Cymru, older people themselves, or housing associations;
- 'Piggy-backing' existing Over 50's forum events - sometimes this involved running dedicated focus groups or individual interviews; sometimes more informal conversations at a stall;
- Visiting older people's social groups and meeting older people and carers (usually individually – but sometimes in pairs, small groups or couples) who were happy to speak to us at the time or later at their home;
- Home visits and phone interviews with older people identified by Care & Repair Cymru and a faith organisation;
- Phone interviews with older people and carers identified through 'snowballing' of the above contacts and occasionally the personal contacts of the research team.

We were very conscious of the risk of skewing the sample towards those who are most active in local forums and social clubs. Given our timescales and budget and the breadth and depth of our research questions, we decided it was not possible to undertake focused 'outreach' to hear from older people in more diverse settings, such as public houses, cafes and buses. Instead we worked hard to identify some individuals who were not so well-connected, through Care & Repair and through the 'snowballing' of contacts.

## **Data collection**

In total, we held 11 focus groups (although at least three of these were 'mini-groups') and 38 one-to-one interviews (mostly face-to-face, but some by phone). Two focus groups were conducted in Welsh by an experienced researcher and supporting note-taker; one was done through a Somali interpreter.

Focus groups typically lasted for between 1.5 and 2 hours (though some at existing events were shorter than this); interviews varied enormously from 15 minutes speaking quite informally at a lunch club to more than an hour spent in someone's

home. We produced a simple consent form (in both Welsh and English), which set out people's rights within the study.

We had a budget allowance to cover older people's travel expenses and a £10 High Street Shopping Voucher as a thank you to participants. We did not offer vouchers where we 'piggy-backed' existing larger forum events (since this would have exceeded our budget); where we dropped into social clubs and had a series of more informal conversations with attendees, we tended to donate one or more vouchers to the club to be raffled.

We asked each participant to complete an anonymous demographic questionnaire at the end of the interviews/ group discussions.

We exceeded our target to speak to 100 older people and 30 carers, though we found there was considerable overlap between these two groups since many older people were themselves carers. The demographic breakdown of these participants is presented in Appendix 2.

## **Recording and analysis**

We used a flexible mixture of audio recording and note-taking to record our conversations, depending on acoustics, setting, availability of note-taker, and participant and researcher preference. Researchers or note-takers either wrote up their notes or our Research Assistant produced a summary based on digital recordings.

Demographic questionnaires were entered into and analysed using a Microsoft Excel spreadsheet.

The research team identified 'nodes' (themes under which to structure our data analysis), based on the topic guide and themes which emerged when reading through all the notes. The write-ups were then 'coded' (with data attached to each of these themes) by our Research Assistant, using Dedoose - a secure online collaborative tool for qualitative and mixed methods researchers. Re-reading of the write-ups by the research team also allowed for the identification of pertinent case studies and a check to ensure all relevant themes had been captured.

## Appendix 2: Demographics of our sample

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We spoke to 135 people.

In this section, we present a summary of the quantitative data collected through the anonymous demographic questionnaire we asked each participant to complete.

### **Carers:**

We interviewed 22 people in their capacity as carers; however, a further 30 people also described themselves as caring for another person due to ill health (i.e. 52 in total).

Of the 52 carers, 34 said they had never had an assessment from social services.

37 were women; 12 were men (3 did not provide an answer). The age breakdown of carers is shown in the table below.

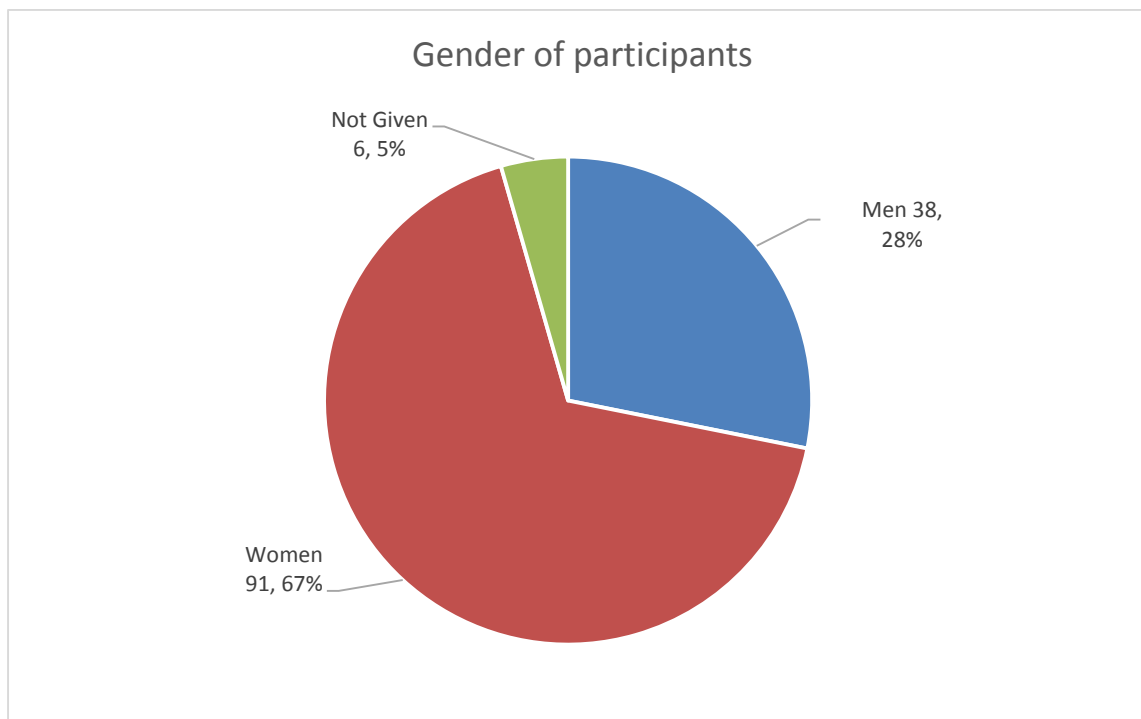
### **Age:**

Although our target audience was people aged 75 and over, we ended up speaking to a significant number of people who were in their 60s and early 70s. Some of these people were carers; others were attending over 50s forum meetings or social clubs which we visited. We decided it was neither practical nor desirable to 'filter' people by age group nor to discount the data we collected from people who we subsequently discovered were under 75.

Age group	Number	Male	Female	How many of them carers?
Under 50	3	1	2	3
50 - 59	5	1	4	5
60 - 69	15	3	12	9
70 - 74	20	6*	11*	8
75 - 79	45	11*	32*	20
80 - 84	25	11*	13*	2
85 - 89	20	4	16	5
95 - 100	2	1	1	0

**\* Remaining participants did not provide an answer**

### Gender:



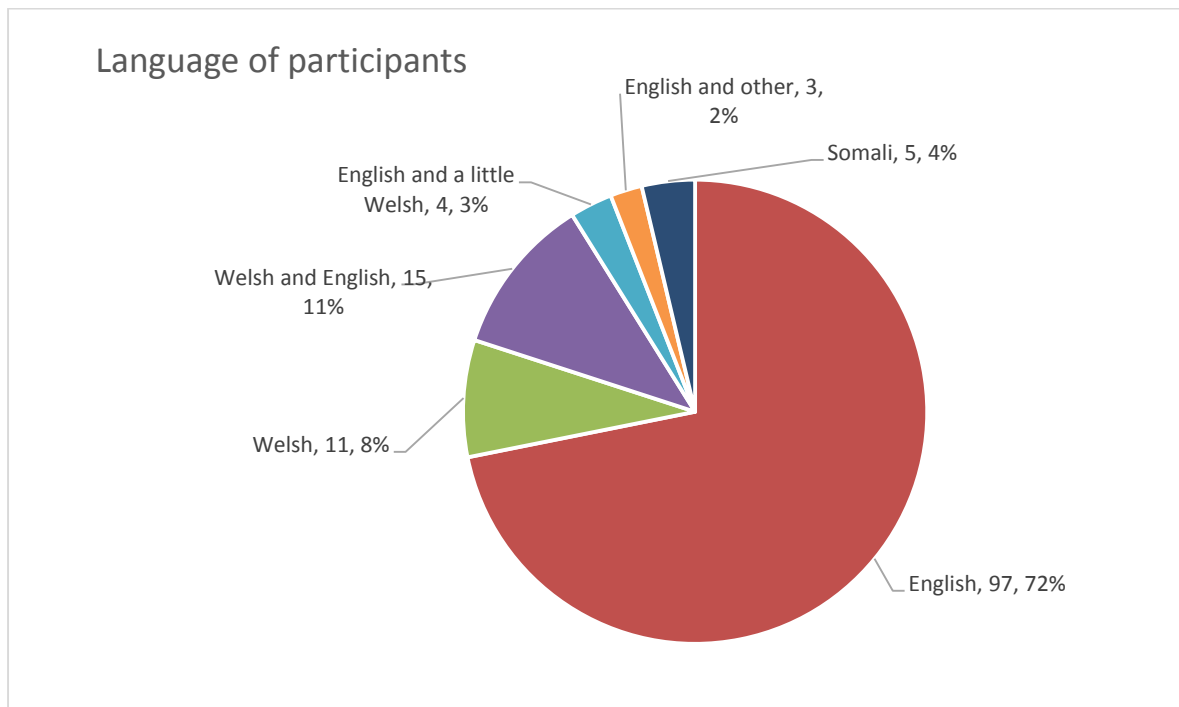
## Ethnicity:

<b>Ethnicity (Self-) Description</b>	<b>No. of participants</b>
Black British	7
British	7
British Asian	2
White European	4
Welsh	8
Welsh Asian	1
White English	9
White British	41
White Welsh	45
No response / blank	11
<b>TOTAL</b>	<b>135</b>

14 of our participants might be described as being from a BME (black and minority ethnic) background. This includes 4 white European people. This represents 10% of our total sample. The 2011 Census data suggests this is more than representative of the Welsh population as a whole, with BME groups making up 6.8% of the population. The census data suggests that BME people (including white Europeans) make up 5.4% of the over 65 population.

As explained on p.9, we did have more informal contact with around 20 older Black and Asian people at a social group we attended (though not all of these people gave a formal interview and completed a demographic form). We also supplemented our data with that collected from seven Polish people living in North Wales whom we interviewed for a previous study. We have not included their demographics here.

## Language:



## General health:

We asked participants to classify their general health

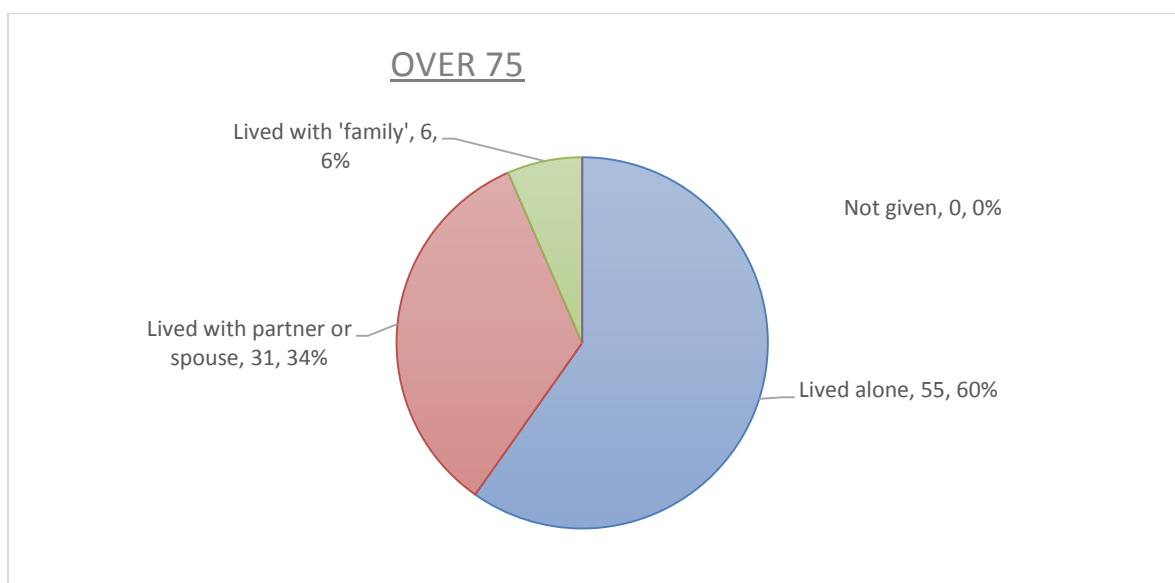
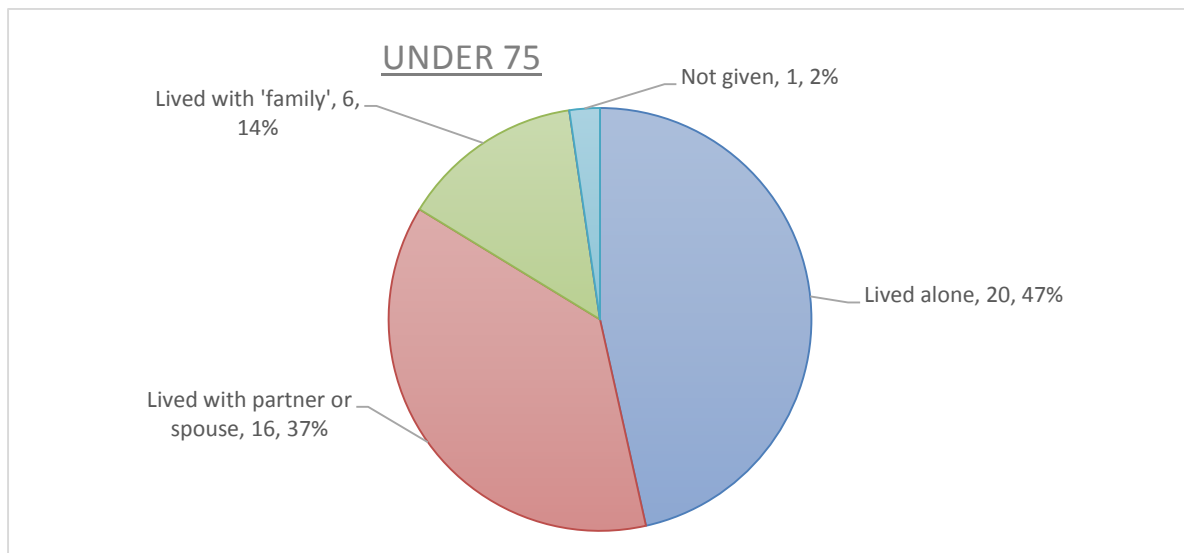
Description	No. of participants under 75	No. of participants over 75	Carers
Very good	9	14	6
Good	15	34	8
Fair	14	33	6
Bad	3	5	1
Very bad	1	1	0
No response	1	5	1
<b>TOTAL</b>	<b>43</b>	<b>92</b>	<b>22</b>

### Long standing health conditions and disability:

85 people (63% of the total) said they had a longstanding health condition or disability; of those, 21 were under 75 (70% of under 75s), 54 were over 75 (69% of over 75s), and finally, 10 were carers (45% of the total carers).

Of those over 75 who told us about their condition, the answers were varied. The majority related to issues around mobility (mainly from arthritis), diabetes and heart conditions. Other stated conditions were high blood pressure, asthma, M.E., cancer, epilepsy and lung related issues such as COPD. Problems with sight and hearing were also mentioned.

### When asked who they lived with:

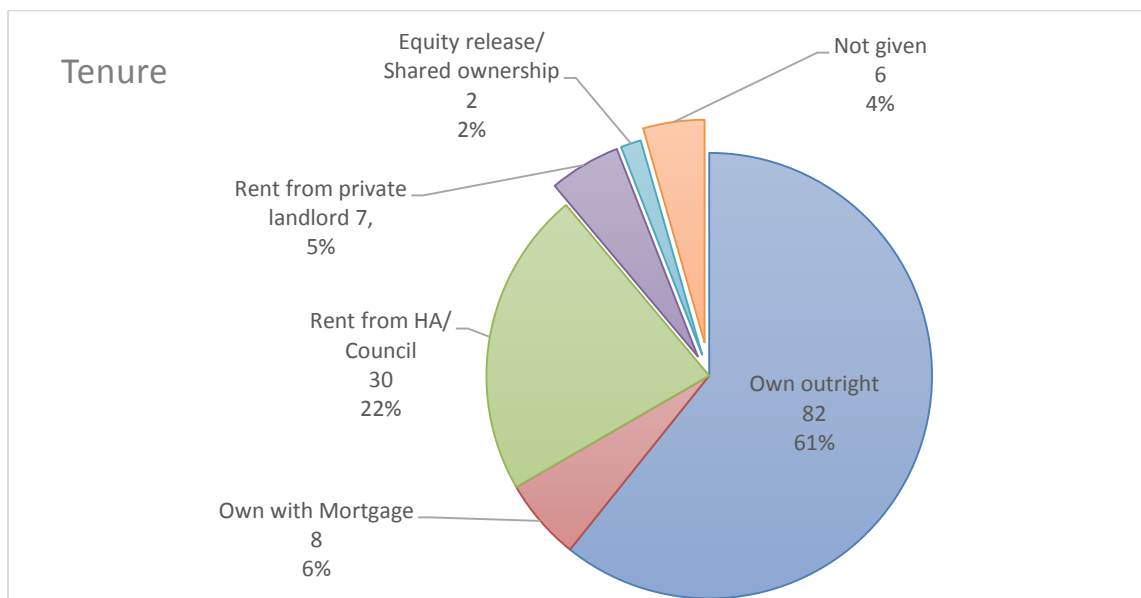




### Have access to a car:

Under 75	Over 75
32 (74% of under 75s)	54 (59% of over 75s)

### Tenure:



Of the 82 who own outright, 43 described their financial position as 'Comfortable'; 22 as 'Fair'; 11 as 'Just about managing'; and only 4 as 'Very good'. Two participants did not give answers.

### Work status:

- 76 out of 135 were retired
- 44 out of 135 who were retired also maintained other activities and roles such as volunteering, carers or part-time working or studying.

<b>Category</b>	<b>Under 65</b>	<b>Over 65</b>
Retired	2	74
Retired & carer	0	15
Retired & Volunteering	0	20
Retired & working part-time	0	1
Retired & Carer & volunteering	1	6
Retired, carer, self-employed & volunteering	0	1
Retired, studying & volunteering	0	2
Carer & Volunteering	0	1
Carer, unemployed & volunteering	2	0
Volunteering	0	2
Working full-time	0	1
Working full-time, carer & self employed	1	0
Working part-time & carer	3	0
Not given	0	3

### Financial status:

Description	No. of participants
Bad	1
Comfortable	62
Fair	38
Just about managing	19
Very good	5
No response / blank	5
<b>TOTAL</b>	<b>130</b>

### Claiming state pension and additional income:

Answers	No. participants
Yes	116
No	9
Not given	10

- 116 out of 135 claimed state pension; of that 116, 82 also received a second income such as a private pension or benefits. No one who received a private pension did so without also claiming state pension.

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