

ssia

Social Services Improvement Agency
Asiantaeth Gwella'r Gwasanaethau Cymdeithasol

Hearing the voices of older people in Wales: Summary



What we did and why

During 2015, a group of independent researchers was asked by the Social Services Improvement Agency (SSIA) to find out what helps and what gets in the way of wellbeing for older people and those caring for them. SSIA was particularly interested in hearing the views and experiences of people who are beginning to experience challenges in their lives and may be 'on the cusp' of needing help from services.

We began by searching for and reading studies which had already been done on this topic and producing a publication called *The Anatomy of Resilience: Helps and hindrances as we age*. This evidence review helped us to identify some of the things that help older people to retain their well-being and independence, and also reduce the risk and impact of crises. These included:

- Relationships
- Psychological resources (or 'inner strengths')
- Finance
- Physical health
- Home
- Community
- Information
- Work and learning.

We also identified the most common pathways that lead older people (unplanned) into long-term care. Some are *incidents* – falls, accidents, bereavements, or experiences of crime - that may change a person's resilience and well-being overnight. Others tend to be *gradual processes* – loneliness and isolation, loss of confidence, a deterioration in health and/or memory. Often it is a combination of several of these changes which can trigger a crisis.

What happens next for individuals seem to depend partly on:

- a) the factors which promote resilience (from the list above) – where they live, whether they enjoy supportive relationships, whether they have what might be described as a 'resilient personality' and so on; and partly on:
- b) the extent to which opportunities for prevention are taken or missed through their contact with services and community groups. This may, for example, include finding out you are entitled to a benefit, being put in touch with a carers' support group, or having improvements made to your home to make it easier for you to manage.

In summer and autumn 2015, a small team of researchers went out to different parts of Wales – North, South, East, West and Central - to hear the views of 135 older people and their carers. Most of the older people were aged 75+: few were in touch with social services, although most had longstanding disabilities or health conditions. We had conversations in Welsh with 19 people.

What did older people and their carers tell us?

We started many of our conversations by asking people what a 'good day' involved 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.

What were the fundamental building blocks of a good life?

Being independent: people did not want to have to rely too much on other people; they valued being able to get out and about and being able to move around their homes without needing someone else to help them. Those we spoke to were very clear that they did not want to go into a care home.

Feeling good about yourself: 'being happy' often involved being able to continue to do 'your thing', 'keeping your mind', and maintaining a strong sense of who you are through a life story which brought meaning. Faith and spirituality played a big part in this for many.

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

Being connected to other people: there was huge diversity in the relationships that mattered to people – friendships with younger people, neighbours who 'pass tomatoes over the garden fence', shopkeepers who say 'hello', as well as partners, family and long-standing friends. Some had a thriving and outgoing social life; some felt isolated and lonely; others just enjoyed their own company.

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

Being active: being able to participate in interests and pleasures which give meaning to life; for some this involved formal classes or group activities; others were happy to get on with their individual hobbies but most people agreed it helped to have some kind of routine to structure their time.

Being well: Managing pain, and coping with changes to energy levels and memory were common themes here; maintaining confidence and managing worry was critical, and people also valued feeling safe and secure.

Relationships

Coping with bereavement and loss were recurring themes; though we did also hear about some new romantic relationships.

"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'.

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, busyness or geographical distance. Many people were worried about asking too much of their children; some felt more comfortable asking friends to help.

Many of those we spoke to were caring for a partner, parent or sibling – or had done so up until they had died or moved to a care home. We heard how dementia (and other conditions or medications which affected the person's personality) tended to make this very challenging emotionally. Carers (and cared-for) often had to come to terms with role reversals; sometimes they had to care for more than one person at the same time, but they did not always see themselves as 'carers', just partners, daughters, brothers, etc.

Caring was made easier when there was:

- Some element of mutual support;

'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.'

- Acceptance (by both parties);
- Ongoing interests and contacts outside of the caring relationship;
- Support to achieve consensus in decision-making; and
- Learning practical ways of coping with conditions, especially dementia

What helps or hinders older people achieving wellbeing?

Transport: over half of those we spoke to still had access to a car – those in rural areas felt this was essential; although there were criticisms of bus services, the free bus pass was very popular and we got the impression that buses can also be key social hubs for older people.

Home environment: being able to remain in your own home was central to maintaining control for many, though upkeep, utility costs and accessibility were often challenging. Some had already 'downsized'; others were considering it – a convenient location was the key factor here for most.

Neighbourhood: 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 all impacted on wellbeing. Many – especially those in longstanding and/or Welsh-speaking communities – felt that the profile and dynamics of their neighbourhoods had changed in ways that threatened their ability to remain independent.

Money: some people told us that poverty was causing them to feel anxious and isolated; others (particularly low income owner occupiers) were in the 'squeezed middle'. Others had a decent income and some savings and felt this enabled them to take steps to promote their own wellbeing and to make the most of life without having to wait for services.

'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?'

Information Technology: Some people were using the internet to improve their wellbeing in a range of ways, from ordering food and other shopping to be delivered online; using Skype to keep in touch with dispersed family; or emailing fellow members of social groups. However, fear of scams was a key barrier here, along with knowledge, skills and confidence; cost; poor connectivity; and disability (especially arthritis and visual impairment).

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

What did people think about Social Services?

- Some people did not understand Social Services' role in relation to older people;
- Others did not see it as relevant to them;
- Some 'dreaded' letting statutory agencies into their lives as they feared losing choice, control and independence;
- Others are 'careful planners' and want to understand what their choices might be further down the line (even though they may be self-funders who will need to pay for their own care and support).

Those who had had some experience of Social Services, either directly, on behalf of a friend or family member, or through hearsay were often critical of:

- **Bureaucracy:** long waiting times, being 'passed around', confusing eligibility criteria, inflexibility, and complex forms and processes;
- **The assessment process:** asking the wrong questions or not really listening to the answer; starting with what's available rather than what's actually needed:

"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 [Social Services] have got in the store cupboard!"

- **What is on offer not being the right kind of help:** this was especially true for carers who did not want domiciliary carers coming in to get their loved one up or put them to bed at odd times, but wanted something different, like a sitting service or some occasional respite.

What did people think about the NHS?

Unsurprisingly, people reported diverse experiences at the hands of the NHS, though we did hear of many examples of 'missed opportunities for prevention'. In these, people had not been given key information and advice; or hazards in their home (often directly related to their health condition) had not been flagged up.

"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."

What did people think about voluntary organisations?

Most of those we spoke to trusted the voluntary sector more than than the statutory sector. There were some criticisms of poor communication or duplication between voluntary organisations. However, we heard many examples in which people had made contact with a voluntary organisation which had supported them to access a range of different services, from benefits advice to home improvements.

"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 [from voluntary agency], she knows all about it ..."

Information and Advice: was crucial to being able to plan ahead. Some people said they simply did not know where to begin; some do not have the confidence, the language or the time to find out.

"We are the people who do not shout".

Information was not always accessible; sometimes it was not passed on. Friends, family and social groups were key sources of information and advice.

Conclusions

Five themes came up time and time again from our review of previous research and in our conversations with older people and their carers:

- 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.

The ideas for change that came out of this project are summarised in the table overleaf.

Lever for change	What it means	Relationship to what older people and carers said
Devolving choice and control to citizens	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)?	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.
Supporting and drawing on the role of community level organisations and facilities	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.	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.
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.

Lever for change	What it means	Relationship to what older people and carers said
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).
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.
Closer working between Social Services, health and other public services.	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.	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.

Lever for change	What it means	Relationship to what older people and carers said
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.
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.

Lever for change	What it means	Relationship to what older people and carers said
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.
Supporting Carers	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.	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.