Revolutionising ageing at home together

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It is a privilege to speak to so many people who have lead, influenced and brought about change for people in every corner of this country.

At ALONE we support older people to age at home. We are a national organisation and this year we will support 8,000 older people across the country who are struggling with issues such as loneliness, housing and health difficulties, accessing services, and fuel poverty.

The first thing to say is that I wish we were not a charity. We don't want anyone to have to rely on charity. The people we serve have worked, or in some cases struggled, all their lives. For others, things have changed as they have gotten older and they need support, and for some, it's just individual events which have happened which leads to them coming to us.

We also don't like the affect being a charity has on how we and the people we serve are perceived, treated and valued by Government. Older people should expect and get top quality services from us all in the NGO sector. A question for another day is whether core Government services like hospitals should be considered charities at all and is their implied independence helpful.

Working in this sector changes you when you realise your own privilege and you wish others could have the same experience so they might see things as we do. I feel that so many people object to things like social housing because they don't understand that large numbers of people will work all their lives but never be able to afford to buy. They don't know what it's like to live on low wages while still striving to be a good citizen. We don't see what life is like outside of our own fishbowl a lot of the time, and that can be true of all of us even within this sector.

There are obviously others who put forward alternative views, especially in housing, in their own interest, but they are a small but powerful minority.

We must claim back narrative with the public on housing, health, and ageing. These are universal themes that the vast majority of the public are unified on and look to us to build the solution. Current narratives are sometimes used to prevent change or encourage more investment in the wrong places.

Our starting point is that everyone wants to do the right thing and will go with that right thing if our services and proposals have the vision, are effective, and are backed up by the facts.

We own part of any solution and yet must have other voices as we build services from the people out. It is always important to engage with those who you feel have been opposing change. Incorporating some of their ideas and reducing their resistance is key to success.

The facts and what is the right thing to do doesn't always change things – but how we present them does. So that means starting the change with us, and how we act, deliver and influence others. We must provide the leadership and take the risks for the changes we want to see.

So many here have done that so all I can do today is to share my and ALONE's vision of how to do this. While we still draw from our past our values and our ethos, we have radically changed how we do that and how we respond. Innovation is what makes us special: meeting emerging needs, helping to define and then scale solutions and influence changing policy. So as an NGO that provides services and campaigns, we can never lose that edge.

We work not to blame, not to make people wrong, but to change things and always to progress things in the direction that will improve the quality of life for the people we serve.

We focus on the issues people come to us for, including:

- · Housing with support needs and living conditions
- Home care, so you can be treated and supported in the place you call home

- Loneliness
- Finance and pensions
- Technology and partnership, where we'll drive to turn the system on its head

We need to discuss some of the obstacles that have resulted in the situation we find ourselves in today, and which will ultimately impact our ability to meet the needs of our changing demographic. Some of these are incredibly simple, basic obstacles which we still haven't overcome.

The first challenge, simply, is ageism in our language. As we know, ageism can be insidious. It's peppered throughout our language. In a New York Times article a few years ago someone asked a marketing director what language should be used in talking about people age 65 and older. Should we call them "seniors"? "The elderly"? "Older adults"? Something else?

She replied, "For heavens' sake, don't call them anything. Let's talk about their interests and values."²

How often do we discuss older people in the context of their interests and values?

In contrast, I want to show you some headlines in the media over the last year related to ageing.

- 'Need to 'bite the bullet' on bedblockers'³
- 'Bed blockers occupy dozens of Dublin hospital beds'4
- 'Pensioner (82) body left undiscovered in sitting room for seven months, inquest hears' 5
- 'Looming pensions time bomb will lead to €3bn deficit in social welfare fund'⁶
- 'Ancient and active: are older staff in the workplace to stay?'⁷

https://newoldage.blogs.nytimes.com/2012/04/19/elderly-no-more

https://www.irishexaminer.com/breakingnews/ireland/need-to-bite-the-bullet-on-bed-blockers-892476. html

https://www.98fm.com/news/bed-blockers-883030

https://www.independent.ie/irish-news/pensioner-82-body-left-undiscovered-in-sitting-room-for-seven-months-inquest-hears-38604402.html

https://www.independent.ie/business/personal-finance/pensions/looming-pensions-time-bomb-will-lead-to-3bn-deficit-in-social-welfare-fund-38669374.html

https://www.ft.com/content/d651e552-d30e-11e9-8d46-8def889b4137

Even the seemingly positive story about older people staying in the workplace for longer put the word 'ancient' in the title.

We are also well accustomed to the pictures which accompany articles about older people. This image of hands interlinked⁸ must have been used thousands of times alongside articles like this calling older people bedblockers, pensioners, ancient, and 'occupying' hospital beds.

Some of this language is particularly off-putting. When have you ever heard hospital patients being described as 'occupying' a hospital bed? People are unwell and they are in hospital, and generally they don't want to be there any more than anyone else. But by describing people as bedblockers we forget that there are people behind the waiting lists. When we talk about delayed discharges we are changing the name, but not the system. We describe older people as 'pensioners' in articles describing those tragic situations when someone's body has been found a number of weeks or months after they've died, rather than as men and women.

We also angle blame towards older people rather than taking responsibility that the needs of the public in health care and housing and other areas have changed and our services need to respond before it is too late and they are overwhelmed.

Our language shapes people's beliefs and ultimately their actions. So many children and older people live in deprived circumstances and there is no widespread chatter or outrage. In some cases we are serving the same children in old age. That is how slow change is.

As we have seen across the water in the US and the UK, language has a huge impact on public perception and opinion. We need to examine the challenges that older people experience not with a tone of blame, but with empathy. We need to focus on how we can improve people's experiences and quality of life, not how we can reduce waiting lists or defuse pension bombs.

The National Positive Ageing Strategy is still without any funding, six and a half years after it was launched. We see support for older people in Budgets

https://www.irishtimes.com/life-and-style/health-family/the-old-country-get-ready-for-an-ageingireland-1.3993009

tends to be reduced to whether a fiver will be added to the pension that year to get the 'grey' vote, rather than anything being done to benchmark the pension to ensure it will safeguard income for older people. And we see discussions of home supports centred around how many additional hours are being delivered, rather than predicting demand and then building up the supply to match. Indeed the fact that more than 900 fewer people are receiving home supports at the end of June this year compared to the year before highlights this.

An ageing population is not a catastrophe and neither is ageing. It is to be celebrated, valued, supported and planned for. We need to change the way we think and act, and we need to plan, now, so that older people can have a positive experience of getting older. We need to balance realistic descriptions of the challenges older people experience with depicting them as the active contributors to society that they are.

The older people we work with have a huge breadth of life experiences and are not to be pitied but supported and cared for. We work with older people who are homeless, and who are in dire financial straits, as well as those living in four and five bedroom houses, all of whom are experiencing their own challenges. Unfortunately, some of these challenges tend to get lost in discussions around bed-blockers, pensions time bombs, and wrinkles.

Here I am going to talk about some of the real challenges older people are experiencing, and hopefully debunk some of the perceptions.

Misconceptions about housing:

- The housing crisis doesn't impact older people. By the time we reach our 60s and 70s, our housing needs are met.
- The grant system in place supports older people whose homes are not suitable for them to enable them to stay at home.
- Older people are 'taking up space' in larger houses within the community because they do not want to move.
- When an older person's needs change and they can't live independently anymore, they should go into a nursing home.

⁹ Pg 5, https://www.hse.ie/eng/services/publications/performancereports/april-to-june-quarterly-report-2019.pdf; pg 4, https://www.hse.ie/eng/services/publications/performancereports/april-to-june-2018-quarterly-report.pdf

The housing crisis doesn't impact older people. We work with older people who experience homelessness or housing difficulties, many who are experiencing them for the first time in their sixties, seventies and eighties. This includes people who have been living in garden sheds, on the floors of mosques, in abusive home situations and the increasing numbers on notice to quit. When rents are high landlords do not want older tenants on fixed incomes, mainly single and who may have support or health needs now or in the future. House ownership is falling and older people will need safety and security in old age. We estimate we need 40,000 units supplied by AHBs and Councils to meet the demand.

For those who will remain in the rental sector they understand the power their landlord has over them and that all of the time they are only 224 days away from homelessness no matter how long you have been living in your rented property. It is one thing to get a notice to quit in your twenties or thirties; it's something else if you're in your 80s. So we will have to grasp the nettle that is long term leases. The narrative is that this is a constitutional issue. Some in the law library disagree and for us this will be a huge campaigning focus for the next election and beyond.

The grant system in place supports older people whose homes are not suitable for them to enable them to stay at home. 58% of older people experience housing difficulties, according to TILDA¹⁰. The most commonly reported problems older people experience with their homes are damp and mould, structural problems and heating difficulties. There is also a percentage of older people who for example, don't have indoor bathrooms.

It's true that there is a grant system in place. However the grants, including the Housing Aid for Older People grant, are often challenging and confusing to access, and accessibility varies across different local authority areas. We have produced a report with 15 agencies to Government highlighting these challenges. Every county has its own rules and the focus is on administering the scheme not on meeting the need of the older people and ultimately both the Department of Housing, Planning and Local Government and the Department of Health welcomed the report. While getting 15 agencies together is work it gives a clear message on the needs for change and reform. Now we have to stay committed to get the changes to the scheme accepted and implemented. The view that we have seen is this scheme could take

https://www.publichealth.ie/news/external-news/tilda-publish-findings-health-and-wellbeing-irelandsover-50s

5-10 years in total to reform, at which stage it will be overwhelmed. We must work hard not to let this happen.

Older people are 'taking up space' in larger houses within the community because they do not want to move. 1 third of older people live alone in homes with four rooms or less. 11 That would be a home with a kitchen, sitting room and two bedrooms.

Research has shown that 15-to 25% older people would opt to downsize¹² and the percentages are slightly different depending on the report.

We are working with people who are living in larger homes, can't maintain them, but can't find alternative accommodation to move to. There is a shortage of one and two bed homes that older people can move to within their communities. The priority for many older people is to remain within their communities where they may have lived all their lives. Rightsizing should be a choice – not a requirement. This creates a wonderful opportunity mainly for private developers as the demand here is north of 56,000 units.

When an older person's needs change and they can't live independently anymore, they should go into a nursing home. Unfortunately, this is the reality for many older people. But it shouldn't have to be. Ireland is lacking in supported housing options for older people that enable them to live semi-independently but which offer them some level of support. We see more options like this in the UK. So we need a new model of housing with onsite support for both urban and rural as a positive choice when someone can't stay in their own home. Again as an NGO housing with support has been, and will be, our housing focus going forward as there is a huge gap in service provision and the demand and need is high. This is an example of where NGOs are vital. It took two years working with others to get a demonstrator model in Rebuilding Ireland and now while that site goes to planning we have to propose new funding models to Departments and to financial markets so this can be scaled. This is the risk we take and leadership we feel is necessary to bring about change. When this is done the others will follow and we will only be a small supplier but we will have served our purpose by breaking new ground.

https://alone.ie/wp-content/uploads/2018/07/Housing-Choices-for-Older-People-in-Ireland-Time-for-Action-1.pdf

https://www.irishtimes.com/business/economy/most-older-people-not-prepared-to-downsize-study-finds-1.4081936

Misconceptions about health and health support

- Nursing homes and hospital stays are an inevitable part of ageing
- Older people unnecessarily take up space in hospitals and A&E departments
- Loneliness is not a health issue

Nursing homes and hospital stays are an inevitable part of ageing:

There are dozens of misconceptions surrounding our health as we age, not all of which I will go into here. Many of us have the view that getting older has a linear result in health decline. However, we know also that there are other factors at play here, including our socio-economic status, our family and relationship status, and our life experiences. Today I will just go into the infrastructural elements and those aspects that we come up against most often in our work at ALONE.

Nursing homes and hospital stays are not an inevitable part of ageing, just as not every 85 year old is skydiving and defying ageing expectations. Just 4% of our older people live in nursing homes according to the Census. And yet, nursing homes are allocated more than half of the funding dedicated for older people. The mindset needs to move to ageing in place first. We will always need, and will need more, nursing homes in one form or another. This is one of the challenges of the success that we are living longer. It is not either or, it is both.

With Sláintecare, the change in focus to providing care in the community will require a huge change in our thinking of how care and support is delivered.

We need to move away from the notion that high level medical support is the only need of our older people and bring the focus back towards providing those medium and lower levels of support which can be catered for within the community, enabling and empowering the older person to stay engaged and well within their community for longer.

Older people unnecessarily take up space in hospitals and A&E departments: Older people are the biggest users of the health services in Ireland. This is not because they want to, but because the availability of care in the community is limited. We need to stop looking at older people as taking up space in hospitals, GP waiting rooms and A&E departments and

recognise them simply as the primary users of those services, and design the services in a way to cater for their needs. Unfortunately part of the reason for annual hospital overcrowding is the lack of funding and support for care in the community.

The Home Supports service is significantly underfunded and under resourced. We have been told repeatedly over the last year that there have been no cuts to home supports, no freezes or restrictions, and yet 900 fewer people were receiving home supports in June this year compared to last year. Every time the winter trolley crisis peaks, there seems to be confusion as to why the small increases in budgeted funding for areas like home support hours isn't having the desired effect, despite the evidence of every year previously showing that home supports requires an increase in funding of €110 million, not a million here and there. Older people should not have to go to hospitals and A&E departments for care they should be able to receive within the community, or that care in the community could have prevented, but under the system that's there, that's often what's required. What is vital is that as we change to Sláintecare, that transitional funding is put in place to manage the needs.

Loneliness is not a health issue: At ALONE we see the full range of experiences of older people with health difficulties: people with dementia, with frailty, with cancer, with any range of health conditions. Nearly half of people over 50 have at least one chronic disease. But a huge aspect of our work is in the areas of loneliness and social isolation. One in three people aged 50 and older feel lonely at least some of the time and one in ten people over the age of 75 have reported feeling lonely "a lot of the time". ¹³

Loneliness can shorten your life, and I think we are only now starting to recognise the impact it can have. Research shows that that older people experiencing high levels of loneliness are almost twice as likely to die within six years compared to those who are not lonely. Lonely people suffer disproportionately with mental health issues, cognitive decline, hypertension, and are more likely to be admitted for residential or nursing care.

We spoke to a woman recently who had up until last year been very active in her community. After she had a fall when she was down in the village,

https://tilda.tcd.ie/publications/reports/pdf/Report_Loneliness.pdf

she ended up in hospital for several months. Now, she no longer goes any further than her next door neighbour's house. The woman is cognitively and physically healthy – but the anxiety surrounding going out, and then the loneliness resulting from that, means she is now finding things difficult.

Her face absolutely lights up when she speaks about her volunteer. Recently her volunteer went in and did yoga with her in the sitting room. We are also inviting her to social events in her community and hope she'll start to come to them again.

Social engagement is key to a good life and we need to recognise the role it plays in maintaining the health and wellbeing of older people. So in response we have activated the community and gone from 400 volunteers to 2,000. We will in the long term have 9,000 volunteers who will also engage people in social activities and help with practical tasks. This is only meeting 10% of demand so we are training, supporting and helping other 40 local agencies to do what we do.

Misconceptions about pensions

- There is a pensions time bomb.
- The State pension covers all your costs as you get older.

There is a pensions time bomb. For me this is one of the most damaging narratives that expresses the success of the aging population, those who built our economy, as a burden.

It's true that as our population ages, pension costs to the State will increase. But this doesn't mean there is a time bomb, and the characterisation of it as a time bomb just highlights the negative perception we have of the cost of ageing.

The Socio-Economic Review by Social Justice Ireland shows Gross Public Pensions going from 5.1% of GDP in 2020 to 5.8% in 2030 to 6.7% in 2040. It peaks at 7.4% in 2050, down to 7.2% in 2060, and down again to 6.6% of GDP in 2070. Overall it goes from 5.1% in 2020 to 6.6% of GDP in 2070. When one looks at the total age-related spending it goes from 15% of GDP in 2020 to 19.3% in 2070 (having peaked at 20% in 2060). 14

Pg 42, https://www.socialjustice.ie/sites/default/files/attach/publication/6096/chapter4.pdf

These are noteworthy increases – but they are not out of the ordinary in terms of OECD countries. If we plan properly not just for the increases in pension spending but in all age-related spending, through measures such as broadening the tax base, there is no reason that this has to be a time bomb. Looking at it in that light, all it is is a demographic change that we have to make a shift in our spending for.

The State pension covers all of your costs as you get older. Currently older people receiving the Contributory pension receive €248.30 per week and those receiving the Non-Contributory pension receive €237. The poverty line in Ireland is €252.11. 15

While the degree of income adequacy generally for older people has improved in recent years, in rural areas an older person living alone still cannot attain the minimum essential standard of living. According to research from the Vincentian Partnership for Social Justice, "The income from the Non-Contributory Pension meets only 83% of MESL [Minimum Essential Standard of Living] expenditure need and slightly more (87%) if in receipt of the Contributory Pension." ¹⁶

Many older people reliant on the State Pension experience difficulties in replacing broken appliances, managing during adverse weather conditions, or if a need arises for extra hospital appointments as their income goes on basic daily living expenses. When someone is reliant on only a State pension and benefits and has no family to support them, unforeseen financial emergencies require a person to look for assistance from charities like ALONE.

We work with a man called Christy, who is now an ALONE tenant. For many years he was in the private rented sector and struggled to manage the cost. There was no central heating, and he went on buses and trains every day on what he called his keep warm trips. Now Christy is in a much more secure situation, but he is still reliant on the state pension and he finds it difficult to manage. Recently, he was left with just a couple of euro left in his pocket to buy food for the week, after he contributed to life insurance. The State Pension is not being increased to match inflation, and it leaves older people to face extremely difficult decisions.

Social Justice Ireland, Poverty Focus 2019

MESL update report 10`9 https://www.budgeting.ie/download/pdf/mesl_2019_update_report.pdf

As well as this, the pension was not designed to cover accommodation expenses. As more of us rent or bring mortgage costs into older age, we will struggle to pay our bills. How will you pay the rent when you retire?

Misconceptions about technology

- Older people and technology don't mix

Older people and technology don't mix: There is a perception that older people want nothing to do with technology. The way the world is built now means that many have to engage with technology in some way or ask someone else to on their behalf. This age group has the most to gain from tech for good.

We provide older people with assistive technology in the home and a tablet device. We find that once an older person is shown how to use a device that is built for them, not only can they use it, but they really enjoy it. Some of the people we have worked with we have introduced to the internet for the first time and they now use it every day.

Older people have a lot to gain from being able to access the internet and technology. We work with 75 year olds who watch old films on Youtube and 85 year olds who get their knitting patterns on Pinterest. We also need to remember that today's 60 year olds, many of whom are still in the workplace and up to date with technological advances, are tomorrow's 70 year olds. The concept of having technology in the home will not be new to them, but expected by them.

Technology will not replace human contact and no one expects it to. But it will be an add-on to support structures to enable pre-emptive and ongoing support. For example, our sensors and technology can highlight to us if someone has had a fall in their home, if someone is not going out as much as they used to, or things like if the temperature is consistently too low. These are not supports that are currently being provided. They're not replacing a person that was doing the same thing. Instead, they link the person into ALONE support staff much sooner than would otherwise have happened. Technology for older people will play a vital role in support provision going forward.

How ALONE are revolutionising ageing at home

These are just some of the common misconceptions around ageing and older people that we need to address. But we also need to look at where are we going, how we are going to plan for our changing demographics, and what needs to change for us to address the needs of older people.

Part of how ALONE is playing our part to address these challenges is in expanding our services and changing our ways of working.

We are mapping services and demographics across Ireland to identify where the needs are and focus on implementing services in those areas through partnership and collaboration with local agencies and developing services on the ground.

This is maximising resources by aligning geographic need in hard to reach areas and developing common practice models for better value for money. We are currently proactively approaching services in areas with high density of need to work together to address gaps in services to meet the current and future needs of the ageing demographic.

We are also working on streamlining services for older people. There are hundreds of organisations in the community and voluntary sector working in different areas to support older people. Often these organisations might have just one or two people working for them, on small scales, but as a collective, there are people and resources positioned nationwide.

We offer a range of services delivered through collaborative approaches to ensure that an older person who chooses to age at home gets the services and supports that they need. We develop key partnerships between statutory, community and voluntary services which will enhance services for older people across Ireland. We support other agencies through computerisation, training and partnership and our assistive technology provides older people with security and support to self-manage and share information on health and well-being with family and other health professionals. Over the next 4 years we aim to computerise 100 organisations.

We have developed a national infrastructure model which consists of a range of ALONE service hubs. Each service hub places the older person at

the centre and ensures that they have access to all the necessary supports and services that they require to age well at home. Our hub model is currently identifying gaps in services across Ireland and enabling targeted service delivery to those most in need through consolidation, partnership and developing services on the ground.

ALONE's infrastructure model is scalable, transferable and replicable. Our national infrastructure focuses on delivering services through a collective of healthcare providers, community services, local authorities, approved housing bodies, and social enterprises all working together, in turn avoiding duplication and streamlining services for older people. We provide support and training to 62 external community-based services nationally, with an additional 50 cross sectorial formalised partnerships across Ireland.

So, ALONE is playing our role in consolidating the sector, targeting our resources and working to expand to meet the demand. But one organisation can't meet the needs of our ageing demographic alone and this is why we need to build our partnerships and forge our connections, because we have to pool our resources. We need to consider the role not only of the NGO and voluntary sector, but of the public and private sectors. We need to ensure that older people and the commissioners of services get both value and choice. In our housing models and in technology we may in the future set up or apply the principles of social enterprise to balance our income and ensure we can still achieve our purpose as an NGO and innovated and meet emerging need.

What do we need from the public sector, ourselves and Government?

- The National Positive Ageing Strategy launched in 2013 and there has still not been any ring-fenced funding for implementation. We need to recognise that funding for services and strategies needs to work towards meeting demand rather than minimal increases year on year, which don't help to solve the problem.
- We have great resources in the form of the community and voluntary sector that need to be utilised and invested in. Systems need support and people to work together to have agreed models and standards.
- As we've mentioned, areas like housing, home supports and health are crying out for further investment. We need to recalculate what our spending needs should be for older people and increase the

overall budget, while streamlining the services and resources we have to get the best possible value for money. Small increases in each Budget so that we can say "we're doing something" aren't enough. If we can't meet the demand now, without a significant shift in mindset we will not come close to meeting the demand in 2030, 2040 and beyond. Budgetary forecasts need to forecast with demand in mind.

- A change in mind-set and language with regard to the needs of older people and the services we need to provide them with. Planning of services for the older person is the first priority ahead of Government and administrative structures.
- We need to see the streamlining of policies and services for older people. Some of these policies and services are in conflict with each other and in competition with each other for finance.
- Partnership and inter-departmental working needs to be prioritised. It was great to see the Department of Health and the Department of Housing, Planning and Local Government coming together last year for the Housing Options for Our Ageing Population report, but this needs to happen as a matter of procedure. Implementation needs to be by the collective. Government bodies are very comfortable talking internally or to each other, but our sector needs to be seen as an equal partner which has great skills and insights to offer. NGOs should be encouraged to keep meeting emerging and changing needs, thinking nationally and acting locally.
- A recognition that currently we are not meeting demand for vital services. We need to acknowledge that this is not just about maintaining our service level provision and increasing this in line with our population changes. Our service provision particularly in the areas of health and housing are not by any stretch of the imagination sufficient for today.
- If we continue like this, we also need to further consider the role of the private sector in health care and housing. This is a relationship that needs to be explored further.

In order to achieve this, we need to change how we talk about ageing. We need to balance realistic descriptions of the challenges older people experience with depicting them as the active contributors to society that they are.

Of course, we have an ageing population. Of course, we must recognise that we need to prepare for that, and we need to make huge strides to meet the challenges older people are experiencing in this country today. And we need to put the supports in place.

But we also need to recognise that it is doable and that the challenges experienced by older people are ultimately solvable. We need to work together to provide solutions.