

SSP 45

Ymgynghoriad ar flaenoriaethau'r Pwyllgor Llywodraeth Leol a Thai ar gyfer y Chweched Senedd

Consultation on the Local Government and Housing Committee's priorities for the Sixth Senedd

Ymateb gan: Jackie's Revolution

Response from: Jackie's Revolution

Jackie's Revolution

"Growing older should not cost us what it means to be human"

Priorities for the Local Government & Housing Committee Jackie's Revolution Group consultation response

Jackie's Revolution response to the Senedd's Local Government and Housing committee's consultation which seeks views on potential priorities over the sixth Senedd.

We are very pleased to be providing a response to this consultation as it will be our first as a new group and social movement for significant change in housing, care and support for older people.

Our Background

In April 2020 a group of 7 people around the UK (Including 2 from Wales) came together to discuss their concern about their future lives. They wished to challenge the status quo, to openly declare the uncomfortable truths about the institutionalisation of citizens under the guise of care, and they are now intent on providing a new vision and direction for change. and drive innovation (social, economic, technological, and humanistic) for change.

The group is now called Jackie's Revolution, created as a social movement, and stands ready "to ensure we have the lives and deaths we want and deserve in late adulthood." Their discussed and agreed vision is "for a society in which citizens, as they advance in age, are no longer viewed as objects of care, a 'challenge' to community and public services, or relegated to live in institutions as a solution to society's inability to meet their individual needs."

Their work has inspired more people and has moved into its next phase whereby we have a Steering Group and an Action Group of 7 of which 4 people live in Wales. Its founder member is Jackie Marshall-Cyrus, previous Director of the Long-Term Care Revolution at Innovate UK, and the Wales members are Lorraine Morgan, past lay appointed member of Ministerial Advisory Board on Ageing, Member of the Housing Expert group and Chair of Gwent Citizen Panel, Andrea Nicholas-Jones former Head of Strategy for Older People Welsh Government, and Sara McKee

Founder of Evermore Well-being & Evermore Global and past Chief Operating Officer at Anchor Trust.

All of our group have significant experience as researchers, managers, educationalists and practitioners in the care and support of older adults in the latter stages of ageing in society. A significant number of us have experience of housing organisations at a strategic and operational level.

After much discussion we have decided that the future of long term care and support provision for older adults must be housing led, but needs some indepth analysis with the Health and Social Care Committee as the long term care and support agenda is integrated.

Our group's view is evidenced in and supported by :-

- Housing Lin's Jeremy Porteous, and in particular their Report with King's College London into the Long Term Care Revolution 2013.
- Professor Judith Phillips OBE who led the Expert Housing Group between 2015 and 2017 produced the Welsh Government commissioned Report AGEnda as well as "Housing and Ageing: Linking strategy to future delivery for Scotland, Wales and England 2030"
- Gwent Regional Health, Social Care and Housing Strategic Partnership Report "The Appropriate and RightSizing Approach" by Julia Osmond, Public Health Wales, and the subsequent Gwent Regional Partnership Board Housing Group, set up to discuss the implementation of its recommendations.
- British Society of Gerontology President who can provide relevant literature and research findings.

One concerning issue which does inhibit how Wales addresses the de-institutionalisation of care and enables older adults to live in accommodation of their choice is the large shortfall in appropriate housing options outlined very clearly in January 2020. These were from the Welsh Government commissioned report from Housing Lin "Assessment of the demand for specialist housing and accommodation for older people in Wales". A lack of housing options for older people was outlined clearly in 2017 by Professor Phillips' Report and her report provided robust short and medium term objectives to create strategies and actions to support older people "staying put" or "moving on" as well as housing market options to enable well being. The Report had been stimulated by an earlier report from the Ministerial Advisory Forum on Ageing in 2014.

Wales is the nation which we feel can test our ideas first. These ideas have been formulated into a mission which is to reset the default mode from that of institutionalised care of older adults, by catalysing innovation and public demand for

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alternative forms of community-based lifestyles and support services in later life for all UK citizens by 2030.

We aim to provide leadership and lend to collective expertise in setting a coherent, attractive and compelling vision for the future of later lifestyles and support. Through partnerships and in collaboration with multiple sectors we stimulate and inspire industry, academia, and policymakers to create eco-systems and infrastructure for alternative lifestyle choices fit for 21st-century living. We intend to drive the demand for options enabling people to choose how they live and die in the later stages of the life course. We believe that the current system of institutional living breaches the human rights of UK citizens and their families.

It does not have to be like this. We propose that people can live and die in their own homes, neighbourhoods, communities, or places of their choosing, whatever their support requirements or medical conditions.

The evidence and the recommendations/solutions from Professor Phillips' Report have already been shared but now need to be discussed in the light of the Gwent RPB Report and its group's work together with the Health and Social Care Committee. To this Committee we have suggested a rigorous indepth study of institutionalised care provision which at present is not fit for purpose and appears to be the 'status quo' for older adults whose needs become more complex. "Putting" an older person into a care home where there are no housing options is the ultimate ageism.

Our rationale for a housing-led solution is outlined in the solutions section of our response to the Health and Social Care Committee consultation on priorities for the sixth Senedd. We attach the response in the following pages as this is a cross cutting issue.

We wish to test a proven model called Evermore Well being with partners in a Health Board region. This is outlined in the following pages. Staffing will be through a co operative model.

We would be very pleased to present our ideas and evidence to the Committee.

Yours sincerely

Lorraine Morgan

Housing, Health and Social Gerontologist
Founder Member -
On behalf of Jackie's Revolution

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Priorities for the Sixth Senedd

Background

The [Health and Social Care Committee](#) has been set up by the Senedd to look at policy and legislation, and to hold the Welsh Government to account on specific issues. This includes the physical, mental and public health and well-being of the people of Wales, including the social care system.

During autumn 2021, the Committee will be considering its strategic approach and forward work programme. To make sure that we can take account of what you think the most important issues are, we would like you to share your views

1. The initial priorities for the Sixth Senedd identified by the Committee (see below).
2. What other key priorities the Committee should consider during the Sixth Senedd in relation to: health services, social care and carers, and COVID recovery.

How to share your views

To share your views, please complete this form and send it **by 16.00 on Friday 17 September** to SeneddHealth@senedd.wales, or by post to Health and Social Care Committee, Welsh Parliament, Cardiff, CF99 1SN.

You can find more information about how to share your views at the end of this document, including guidance on providing written evidence, information about the Senedd's two official languages, and details about how we will use the information you provide.

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About you

This section of the form asks you some questions about yourself and the capacity in which you are responding to this consultation. This will help us to process and use your information in line with our [privacy policy](#).

Your details	
1. Name:	Lorraine Morgan
2. Email address:	
3. Would you like to be added to the Health and Social Care Committee's contacts list in order to receive updates about our work?	Yes <input checked="" type="checkbox"/>
	No <input type="checkbox"/>
<i>You can unsubscribe at any time by emailing SeneddHealth@senedd.wales.</i>	
4. Please tell us in what capacity you are responding to this consultation.	
I am an individual responding in a personal capacity	
I am an individual responding in a professional capacity (please tell us what your job title is)	
I am responding on behalf of an organisation (please tell us which organisation and what your job title is)	Jackie's Revolution has been set up in past year as a social movement. Its members are all volunteers, and I am, as a founder member, the contact person. My background is as a previous gerontology social care, housing and nursing adviser.
If you are under 13 years old, we will only be able to accept your response if your parent or guardian has confirmed that you can participate. They can do this by sending us an email to SeneddHealth@senedd.wales .	
5. Are you under 13 years old?	
I am under 13 years old	<input type="checkbox"/>

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I am 13 or over	<input checked="" type="checkbox"/>
<p>6. Please choose one of the following options to confirm whether you would prefer that your name is not published alongside your evidence.</p> <p>We will not publish the names of people under the age of 18.</p>	
I am aged 18 or over and I am content for you to publish my name alongside my evidence	<input checked="" type="checkbox"/>
I am aged 18 or over and I would prefer that you did not publish my name alongside my evidence	<input type="checkbox"/>
I am under the age of 18	<input type="checkbox"/>
<p>7. Please choose one of the following options to confirm whether you have agreement from any third parties referred to in your evidence that you can share information that may be used to identify them and that they understand that it may be published.</p>	
I confirm that any third party I have referred to in my evidence has agreed that I can share information that may be used to identify them, and that they understand that it may be published.	<input checked="" type="checkbox"/>
I do not have the agreement of one or more of the third parties I have referred to in my evidence.	<input type="checkbox"/>
I have not referred to any third parties in my evidence.	<input type="checkbox"/>

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Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

Q1. Which of the issues listed above do you think should be a priority, and why?

We are very pleased to be able to contribute to this Consultation.

We would like the opportunity to share the evidence we have collated through our work over the past year and the possible solutions and their source.

Priority - Evidence Based Innovation in Health and Social Care

We strongly support this priority. It is critical that the committee addresses the Social Care agenda from a person centred, holistic & relationship-centred approach.

It is critical that the narrative around Health and Social Care shifts to a rights-based approach, enabling the individual to have real and meaningful choice about where, how and with whom they live their lives.

The current model of costly interventions in the community and institutional care is not sustainable for Government, nor the preferred option for many older people.

The Scrutiny that the Committee can offer will be invaluable in allowing a robust, evidence-based evaluation of the current status quo. In addition, the Committee could reimagine what good support can be to support people and communities to age safely in place.

The Committee proposed inquiry into innovation in health and social care, must be an urgent priority, however it will be rendered meaningless if the same stakeholders, institutions, and services are all that is considered.

There needs to be an open and risk-taking approach to reimagining what the support of the future could and should look like.

Rationale

The nature of care and support for older adults whose needs become complex and/or greater is now steeped in an almost automatic admission to a Care Home for care and contracted provision.

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John Kennedy from the Joseph Rowntree Foundation said in 2012 “One day I may end up in a care home. Does it scare me? Does the idea fill me with dread? Does it you? The issues affecting care homes never seem to change. Why not?”.

These questions have been haunting us over the past year and are now more pressing than ever as the evidence would indicate that nothing has really changed. During the pandemic we have seen older peoples’ human and civil rights, particularly in Care homes violated and trampled over and thousands of older people have died unnecessarily.

If we do not start to rethink institutional long-term care, stimulate innovation, and create new and desirable alternatives which offer affordable choices which meet our aspirations in later life then history will continue to repeat itself.

The Long-Term Care Revolution set up by Innovate UK aimed to change the status quo through disruptive innovation and create new alternatives to institutional forms of long-term care between now and 2020, with a vision for 2040. This was with an overarching ambition to transform long term care in the UK from an economic liability to a dynamic engine of economic growth. Our population in the UK continues to age at an impressive rate, so the time is now to think about quality as well as quantity of life.

In the UK currently a placement in a Care Home when your needs are complex is a ‘fait accompli’ where an older person’s right to a family life and to a private life is ignored.

Too many older people and their family carers go through this agonizing and very stressful situation, moving older people from their home, their community, their family and their informal support structures and mechanisms, and weakening communities.

Now is the time to change the “System”. The pandemic has made existing models in this present System unsustainable. There is opportunity to build back better, or older people will be failed again.

The NHS has been put under such extreme and unprecedented pressure during the Pandemic it cannot cope now with demand. Our ageing population, if not supported to remain safe and well in their community will soon completely overwhelm the NHS. Investment in the NHS is critical but if that is not matched with equal or more investment in community based social care and support it will collapse.

Delayed transfers of care are an ongoing issue and will only worsen as we see the impact of Long Covid on services. The impact of the delays in other critical health interventions that we have seen during the pandemic will lead to system overload.

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The committee needs to seize the opportunity to facilitate the debate on how low-level preventative services from the third sector, which are already provided in local communities and in supported housing can be made comprehensive and sustainable.

The evidence emerging from these already shows that these new services can sustain and improve health and well-being in older adults. (Action for Elders Impact Report 2020)

The evidence for change is persuasive and readily available. In 2017 Welsh Government commissioned report, Our Housing AGEnda: meeting the housing aspirations of older people, from the expert advisory group chaired by Professor Judith Phillips, detailed recommended actions in several areas, including:

- Improving understanding of the housing requirements of older people
- Widening housing choice
- Developing a planning system that prioritises our ageing population
- Making housing more affordable and incentivising change

A core message from the report was that services should be strengthened to support and enable older people to live independently in their homes for as long as possible. It noted that we “need an intersectional, inter-professional and interdisciplinary perspective. No one sector can do this alone and we need to get smarter in how we collaborate – with communities, business and industry, planners and government – to take some of these ideas forward.”

Most importantly Professor Phillips stated, ‘We need to think about the human cost of not doing this, and the cost to the public purse if it’s not done.’

There are many examples of excellent practice in Wales that the Committee could consider when conducting their enquiry:

For instance, recently Gwent Regional Partnership Board (GRPB) set up a Task and Finish group to look at ways of implementing the recommendations for their commissioned report called “The Appropriate and Right Sizing Approach by Julia Osmond at Public Health Wales ABUHB (2019). One of our members is a core member of this group so already there is activity around developing new ways of working which are integrated, consider a co-operative model and the ABCD approach of asset based community development (Russell C 2020). This would link strongly to Professor Phillips Report and recommendations.

The Committee should look at the work that Sara McKee founder member of Evermore Well-being has done as an example of innovation, based on tried and tested approaches from the US, Scandinavia, and Australia.

It involves older people living in a family home setting with a small group of people, usually up to 12. Each person has their own private space but shares communal

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areas like a kitchen and living room. Any care and support provided comes from a co-operative model.

Evidence for Change

The Long-term Care revolution at Innovate UK brought together all the research and information that was needed to change the System, the evidence they have generated is compelling. Some other evidence we have collated is:-

- The present nature of institutional care, its organisational model and the status quo which sees almost the automatic presumption that when a person's needs become complex or too expensive to support in the community the only option is to 'be put' into a Care Home.
- In Wales in 2020 between 24 and 25,000 older people lived in 1,336 Care Homes. This represents about 4% of the total population aged 65 years and over but there is then a threefold increase to 15% of people aged 85 and more. (Carehome.co.uk) However, we see little development of any options, either housing models or health and social care increased packages of care to support people in their own homes.
- While the idea that private companies may play a bigger role in the future provision of health care is highly contentious in UK and Wales, the transformation of the residential and nursing home care has attracted little comment. Concerns about the quality of care do emerge from time to time, often stimulated by high profile media investigations, scandals, or criminal prosecutions, but there is little or no evidence about whether the transformation of the sector from largely public to private provision has had a beneficial effect on those who need the service. (Burton D & West E 2017) And indeed little evidence to show that residential care is preferable, in terms of health and well-being benefit, to losing one's family home.
- The organisational culture in Care Homes continues to be a concern and whilst there have been some initiatives such as My Home Life Cymru (2008 – 2014) to transform that culture it is still based on the medical model of ageing. There is evidence of some good owner managed Care Homes identified through the work of My Home Life Cymru, but this programme exists only in England and recent findings in England show no change in the autonomy of residents. (Pocock 2020)
- There is evidence of Health Boards putting some failing Care Homes into special measures because of poor quality and staffing issues. Evidence from internal market reviews by Regional Partnership Boards show that it is difficult to discover the real owners of some corporate/company managed homes as hedge funds are involved.

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- We have undertaken a timeline of residential care since the year 936. It is disappointing and shocking how little the actual organisational culture and use of private, for-profit model has changed. A serious question must be asked about why the NHS and Social Care sectors who currently commission most of the long-term care have been so slow to develop a culture which promotes innovation. Market shaping exercises seem to assume the status quo will continue indefinitely which is confirmed by the number of care providers now building new larger care homes. Indeed, our First Minister in his previous research role raised the issue of the innate nature of Care Homes for profit (Drakeford 2006). This has not changed at all. Add to this that we now have a crisis of little not for profit ventures to support older adults in their own homes and a health and social care sector seriously short of registered practitioners and support workers.
- The marketization of nursing home care has posed new challenges to governments in collecting and reporting information to control costs as well as to ensure quality and public accountability. (Harrington 2017)
- The poor availability of appropriate housing stock is causing older people to go into Care Home provision – most of which is for profit. (Blood I 2017)
- The evidence from Innovate UK Long term Care Revolution showed that many elements of how we live our lives have been transformed by the rhetoric of choice and control in determining the care needed to live independent and fulfilling lives. But this is not being reflected in how services are being delivered. Older citizens show a strong preference to receive long-term care in their home rather than moving into a nursing or care home and their expectations of autonomy and choice in later life are not currently being realised. These preferences were again itemised in the Welsh Government AGEnda Housing Aspirations for an Ageing Population in 2017 but have not been realised.
- It is a serious issue that while there has been a substantial investment in ageing better; it has involved disconnected thinking and short-term pilots not embedded in community services. Today people want tailored and personal care which is coordinated via one key contact. (Katz S & Peace S 2014) (Blood I et al 2017)
- The institutional mindset is still prevalent in social care and our health system with a medical rather than the social model of ageing and support. Services are not being tailored to meet the personal needs, hopes and aspirations of older citizens. There appears to be a focus on medicalising later life care which ignores the health risks associated with loneliness and social exclusion amongst older citizens.

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- There are a proliferation of partnerships and alliances exploring the ageing better agenda and how to embed social innovation in long term care but again data and experiences are not collated and evaluated, and little seems to be embedded in a new way of working.
- For many carers and families residential care becomes the only option. There is very little consideration of a service culture which would include 'options' 'choice' and 'self-determination' (Innovate UK LTC provocation paper)
- “So, for 20 years successive Governments, think-tanks, charities, public and private sector providers have grappled with one of this country’s biggest challenges – how to make the NHS and social care both fair and sustainable. While it’s funding that has captured the headlines, examining how two siloed services could work better together to maximise the health and wellbeing of our growing population has been at the heart of this decades- long conversation.

We still don’t have a solution.” (McKee S 2020)

Jackie’s Revolution

In April 2020 a group of 7 people around the UK (Including 2 from Wales) came together to share and debate their concern about their future lives. Our ambition is to challenge the status quo, to openly declare the uncomfortable truths about the institutionalisation of citizens under the guise of care and provide a new and aspirational vision and direction for change, and drive innovation (social, economic, technological, and humanistic) for change. Its founder member is Jackie Marshall-Cyrus, previous Director of the Long-Term Care Revolution at Innovate UK, and the Wales members are Lorraine Morgan, past lay appointed member of Ministerial Advisory Board on Ageing, Member of the Housing Expert group and Chair of Gwent Citizen Panel, Andrea Nicholas-Jones past Head of Wales Strategy for Older People and Carers, and Sara McKee Founder of Evermore Well-being.

Our mission statement is:

“To ensure we have the lives and deaths we want and deserve in late adulthood, to reset the default mode from that of institutionalised care of older adults, by catalysing innovation and public demand for alternative forms of community-based lifestyles and support services in later life for all UK citizens by 2030. Human rights are at the heart of this mission”

Our agreed vision is “for a society in which citizens, as they advance in age, are no longer viewed as objects of care, a ‘challenge’ to community and public services, or relegated to live in institutions as a solution to society’s inability to meet their individual needs.

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