

Evidence from Jackie's Revolution Expert group (registered with Wales Co-op and pending Social Enterprise)

The Expert Group that constitutes Jackie's Revolution (JR) welcomes the opportunity to submit evidence to the Senedd Care Home Commissioning Enquiry 2022.

We would like to challenge the idea that improving the market mechanisms is the priority to improving the mechanisms to deliver long-term care in Wales. In fact, we challenge the viability, sustainability, and fitness for purpose of the institutional model of long-term care going forward in the 21st century. We believe it is a social problem and must be stopped. We contend institutionalisation of older adults under the guise of advanced age and medical conditions is the ultimate, most ignored, and entrenched form of ageism in British society. We know it is based on centuries old tradition which in our research we have traced its history back to 936; and has no place in advanced societies.

We believe what is needed is not a refinement of care home commissioning, but planned disruptive innovation to pivot new models, frameworks, and cultures for future generations of older adults in Wales. We have the evidence and the will to provide solutions which we outline later in our paper.

The imperative for this Enquiry is that "Our society must make it right and possible for old people not to fear the young or be deserted by them, for the test of a civilization is the way that it cares for its helpless members." (Buck 1932)

We challenge the Care Home Commissioning Enquiry to begin the process of dismantling the institutional care model as it represents a complete systems failure, and to pave the way for ways of living out advanced years with dignity, personhood, citizen power, and choice.

We believe priority should be given to finding new and alternative ways to deliver home-based, community-led, people-powered, Human Rights-based lifestyles with support in people's own homes.

We wish to present the evidence and imperatives in support of this view.

Jackie's Revolution – Who we are

In April 2020 Jackie Marshall-Cyrus FRSA, former lead specialist for the Assistive Living Platform at Innovate UK convened a group of seven experts in the ageing and social care domains from across the UK (including 3 from Wales) who would stand with her to openly challenge the status quo and dare to declare the uncomfortable truths about the institutionalisation of citizens under the guise of care. This led to the founding of Jackie's Revolution in April 2021. Its operations are delivered by a core team of four (4) domain experts, three (3) of whom are Welsh and reside in Wales. Their backgrounds are based in policy development, gerontology, nursing, disruptive innovation, entrepreneurship, and collaborative programme delivery. We operate on the basis of "6-ship principles", i.e. Leadership, Partnership, Companionship, Kinship, Relationships, and Ownership. The team stands ready to ensure as a generation we live and die where we want and is befitting to us in late adulthood.

Our agreed Vision is:

"By 2030 growing older must not cost anyone what it means to be Human." (J R 2020)

Our Mission is:

"To catalyse the creation of affordable, sustainable, community-based, citizen powered alternative models to institutional care befitting of life in the 21st Century" Human rights are at the heart of this mission" (see Declaration of Rights for Older People WG 2014)

We have decided that Wales with its citizenship, rights and social justice policies is the best place to pilot a concrete solution. We have now shared our vision further in Wales with partners in Housing Associations,(Pobl for any accommodation for events, Melin Homes in direct partnership for proposals, Swansea University (Centre for Innovative Ageing and Arwen Institute) for community development/co-productive research, follow-on participative research with older adults including Cymru Older Peoples' Alliance (COPA) and facilitation of "Sandpit/Ideation" events. An Energy and Digital organisation and others are eager to join us and start the process of our 5-year strategic plan. We have agreed and shared the key components of a new eco-system within a proposed demonstration site to provide and support older adults in partnership and collaboration.

Our Objective

We are citizens who will model an innovative eco-system that harnesses key components which will deliver our vision. These components include environmental sustainability and circular economy principles, affordable adaptive carbon-neutral housing, advanced materials, architecture, town planning and urban design, workforce re-modelling and re-deployment, modern transport systems, waste management systems (industrial, domestic, and clinical), artificial intelligence and machine learning, robotics and autonomous systems, systems thinking and simulation, big data, design, technology transfer and re-application, entrepreneurship and social innovation. We welcome anyone willing to support us to realise our vision. This list is not exhaustive.

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. This is based on robust research evidence, consultation with high level supporters and experience from Innovate UK work. There is an historical, social, and economic imperative to use this work and share our thoughts and evidence with the Committee.

The Historical Imperative

On 5th July 1948, son of the soil Aneurin Bevan gave us a legacy built on the long held ideal that good healthcare should be available to us all, regardless of wealth. **Our goal** is to start to build a legacy in Wales, based on an unshakeable ideal that people deserve to live out their lives in their own homes and communities regardless of age and physical/mental need.

The history of institutionalisation as a way of looking after older adults in Britain began in 936 and we have traced the changes since 936 in a further paper (Marshall-Cyrus J & Morgan L 2022). It is disappointing and shocking how little the actual organisational culture and use of private, for-profit model has changed. A serious question has to be asked about why the NHS and Social Care sectors, who currently commission the majority of 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.

Commissioning more care home places is not the answer for future generations and neither is it at all cost-effective using precious public money. None of us want to live to the end of our days in a Care Home.

We would like to challenge the idea that improving the market mechanisms is the priority when what we actually need is **disruption** to the existing model of long-term care.

The institutionalisation of older adults under the guise of care is a societal problem we choose to ignore. The system is archaic, dysfunctional, unsustainable, not fit for purpose, a drain on local government budgets, unwanted by many, and in many instances breaches people's Human Rights. It no longer represents a judicious use of taxpayers' money or reflects 21st century living.

Leadership, innovation, political will, and appetite for risk are critical drivers for systems change.

The Social Imperative

Research shows that people do not want to be institutionalised in advanced years. The spectre of institutionalisation in later life fills most people with fear and trepidation. 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?".

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, then the only option is to 'be put in' or 'admitted' or be 'placed' into a Care Home. For older adults and or their families who do not want this there is very little in the way of choice or a coherent integrated ecosystem to support them to live out their lives where they wish. Most people want to remain in their own homes and there is evidence to support this in Wales (Osmond 2018 (Gwent RPB), Welsh Government AGenda 2017) as well as over many years. The adage "remain independent in their own homes for longer" is a clear indication of the apathy that pervades the subject. Is it a stretch too far for people to remain in their own homes with the support they need to live their best lives until the end? It is an indictment to society and to the powers that be that we continue to strip people of their homes, their finances, their children's inheritances, their power, their sexuality, their identity, and ultimately their humanity at scale. It has become an accepted practice that has been

normalised through the centuries, and despite the technological and social advancements we have made, we choose to remain blind to this dark stain on the fabric of our society.

We believe that the 21st century, in our time, is the right time to lay a new foundation for enabling older adults to retain their rightful places in society and not on its fringes. We believe that tinkering around the edges of what is a systems failure with initiatives focused on improvement will not move us forward. Historically none has, and we are where we are today. Successive UK governments continue to kick the tin down the road as they believe adult social care is in the “too difficult to do” box, and so a plethora of policy, regulations, “low hanging fruit” initiatives, and reports that bring us back to square one decade after decade with no end in sight. Wales now has a huge opportunity.

Being put into 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. 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 – Ayres S (2012)). So many older people and their family/unpaid carers go through this agonizing and very stressful situation.

It is time to openly declare the uncomfortable truths about the institutionalisation of citizens in structures called care homes under the guise of care, and to accede that the old ways are no longer working. We need reinvention, not refurbishment or renovation. The current institutional model of long-term care is not working. It will not stand up to the socio-political, socio-economic, and socio-technological dynamics of the world we live in today. There is a need to be intent on providing a new vision, exploring new ways, and stimulating new drivers of innovation (social, economic, technological, and humanistic) for real change. It is entirely possible for people to live out their lives and die in their own homes, or place of their choosing. We trust that we have found the political leaders, organisations, and people who dare to take the risk to make it so.

The Economic Imperative

The institutional provision of long-term care is undeniably a lucrative market. The people who reside in such settings are undeniably commodities, not customers. The broad problem market areas in the sector are:

- (1) those requiring care need greater support in choosing a setting and greater protections when they become residents,
- (2) the current model of service provision cannot be sustained without additional and significant amounts of public funding and the parts of the industry that supply primarily Local Authority (LA) funded residents are unlikely to be sustainable at the current rates the LAs pay.
- (3) significant reforms are needed to enable the sector to grow to meet the expected increase in care needs. They are unable to meet it today and the framework for delivery ensures that they will not be able to meet it in the future,
- (4) greater protection of residents' Human Rights and compliance with Consumer Law are needed.
- (5) uncertainty around how much "leakage" is occurring from for profit Care Homes' public funding (and individual older adults' private savings) into shareholders pockets outside Wales – UK Group organisations, and outside UK – Hedge funds. (Kotecha 2019)

Real Economic Cost to Citizens - The costs of the existing model of provision to the citizen is phenomenal. In Wales in 2021 between 25 - 26,000 older people lived in 1,077 Care Homes. (Bolton 2022) 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. 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. The majority (75%) of care homes for older people in Wales are owned by a single owner or an owner who has less than five homes. A much smaller percentage of homes are owned by larger group providers (8%) or by local authorities (17%)². 29% of care homes in Wales for older people are run by organisations based in England.(Bolton 2022). Health Boards are having to support struggling care homes, using extra resources when fees, such as a minimum of £801 per person per week (Laing Buisson 2019) have already been paid. It is suspected that there will be little interest in new single owner managed homes in the sector because of costs and staffing, and there is therefore a significant risk that the large for-profit groups may "snap up" failing care homes or build new ones where the profits will then exist outside Wales and outside UK.

The unit costs of health and social care are evident in the yearly regular figures from PSSi Kent (Jones & Burn 2021). Home care (with or without health care (community nursing input) versus Care Home costs are also available. What is absent is the cost

benefit analysis which includes the proportion of public and individual family's funding paid into Care Home dividends, a considerably amount of which are held outside Wales in group organisations and outside the UK in hedge funds.

A key fact from Kotecha (2019) showed that "Out of a total annual income of £15bn, an estimated £1.5bn (10%) leaks out of the UK care home industry annually in the form of rent, dividend payments, net interest payments out, directors' fees, and profits before tax, money not going to front line care. This is equivalent to the £1.5bn of additional funding for social care promised by the government in the September 2019 Spending Review." According to Kotecha the "leakage" is extremely difficult to identify in terms of clear profit.

Also add the cost to the public purse of this huge industry of NHS and Local Government health and social care assessors constantly reassessing for residential dementia care and continuing health care.

Lack of Control of Costs. While the idea that private companies may play a bigger role in the future provision of health care is highly contentious in UK, particularly in England, the transformation of the residential and nursing home care (labelled as Social Care) from a public service direct provision to a mainly private provision has attracted little comment. And yet it had been foreseen, by evidence from past research (Drakeford 2006) which showed these worries, and which have now been realised. These risks were not acted on, and various Care Home market analysis by Regional Partnership Boards (Gwent RPB 2019) show that it is difficult to discover the real owners of some corporate/company managed homes as hedge funds are involved. 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 & Jacobsen 2017). Arguably changes in regulation and inspection have made no difference to the lives of older residents as there is little research evidence to prove either way.

Commodification of Care.

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 no longer exists and recent findings in England from a longitudinal study show

that despite new Acts, regulation, registration, inspection and standards Care home residents experience a loss of autonomy and a lack of agency; they are often excluded from decision-making. Also, older care home residents have few choices with regard to care at the end of life. Care provision in a Care Home is a commodity as are older adults. In Wales we see this disruption and a new model for later lives as a huge contribution to the foundation economy where not for profit care and support provision would remove the focus on care as a commodity. The commodification of care means that within the commissioning cost using public money there always has to be a contribution towards the profit and dividends received by shareholders.

Health need impacts upon need for social care.

We should always note that a health need impacts on the need for social care. The removal of personal care in 2000 from the nursing role – whereby community nurses were no longer allowed to provide a bath – where the holistic assessment could take place – was removed despite presentations to Welsh Government – in 2000 with the implementation of the Care Standards Act (2000 Wales). This was the ultimate in ageism as it labelled and punished many older adults to a life of reduced access to quality community nursing and being “put into a care home”, so increasing the incidence of separation from partners, family and friends, which was not their choice. During the pandemic we have seen older peoples’ rights, particularly in Care Homes trampled over and thousands of older people have died. The rights of relatives and loved ones to access their families continue to be trampled upon today. People are powerless to see, speak, or be with their loved ones. It is unimaginable that we may find ourselves in such a situation, yet we sit by and see it fit to explore how market mechanisms should be a priority to delivering “improvement’ for an outdated, unsustainable, and unfit health care model.

Quality of Care impacting on Health and NHS services

Concerns about the quality of care do make it into the public domain from time to time, often stimulated by high profile media investigations, scandals or criminal prosecutions. However, there is little or no evidence about whether or not the transformation of the sector from largely public to private provision has had a beneficial effect on those who need the service. (Barron & West, 2017). There is also little evidence to show that residential care is preferable in terms of health and well-being benefit to losing one’s family home. Why is the profit to be made from an older adult’s care included in the costs of long-term care?

We can only imagine the savings in terms of better lives (health and well-being) and not for profit costs by providing all long-term care in a person's home.

Anecdotal evidence from members of our Expert Group, nurses, carers, relatives, and a variety of support networks in the sector point to a level of secrecy and concealment that is shocking and well established. Care quality has been one of the intractable challenges that has plagued the institutional model from the outset. In the 1920s conditions caused so much concern to nurses and medical officers of health that it paved the way for the appointment of the Select Committee on nursing homes (Abel-Smith, 1964). Evidence to the Committee reported on the terrible circumstances of some patients. Should the cloak of concealment be lifted the picture is not that far removed from circumstances today as seen in Dr Margaret Flynn's inquiry for Welsh Government 2015.

The Policy Imperative

The long-standing approach to dealing with the challenges plaguing the system has been policy and regulation, as well as best-practice tool kits. The Re-Balancing Care policy, The Well Being of Future Generations Act 2015 and Social Services and Well Being Act 2014 create an ideal opportunity to innovate radically by disrupting the whole system and creating a new eco-system of care and support for present and future generations.

The Innovation Imperative

In 2013, Innovate UK (now UKRI/Innovate UK) undertook a radical programme of innovation to explore the potential to disrupt the institutional model of long-term care in the UK. The aim was to fund project ideas innovation that would disrupt the status quo of long-term care between now and 2020, with a vision for 2040 in order to transform long term care in the UK from an economic liability to a dynamic engine of economic growth.

The three (3) year programme was funded for £8m. It was delivered in two (2) phases, the first being a National SBRI Challenge for entry into a 'Sandpit' and the second phase being an SBRI Grand National Challenge co-funded with the Economic and Social research Council, and the Engineering and Physical Sciences Research Council. To date, this programme has been the only national innovation challenge to turn its eye to the institutional model of long-term care. It highlighted the dearth of innovative thinking in the domain, the level of risk that needed to be calculated and taken to deliver real change, and power of engaging "the unusual suspects" to generate new ideas.

The innovation agenda continues apace with the Industrial Strategy Challenge Fund's (ISCF) Health Ageing Challenge valued at £96m. The Healthy Ageing agenda now however stops short of people living in the institutional care, preferring to fly the banner of "independent living in one's own home for longer". This is a tacit admission that institutionalisation is accepted, expected, and normalised. Anyone in the ageing innovation field will report that the projects funded by the ISCF's Healthy Ageing Challenge amount to more of the same.

What Wales now has is an opportunity to do something special, something no one else is prepared to take the risk to do, but which has the potential to bring untold rewards to its economy, its society, and to the quality of life of its people.

The goal of innovation is to make positive change, to tackle complex problems to create something new or to make things better for people. Innovation is risky. There is no getting away from it. Yet we forget that risk underpins every major social, economic, and technological milestone in the history of mankind. Leadership, innovation, political will, and appetite for risk are critical drivers for systems change.

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.

We have already submitted two sets of evidence to the Health and Social Care Committee and the Housing and Local Government Committee on our views for the Sixth Senedd programme.

Evidence for Change

As we have stated right at the beginning, this is not just in commissioning care home placements but in reducing commissioning to care homes.

The alternative, and much more rights-based option is care at all levels in the home of an individual's choosing, whether that be a flat, house, housing supported flat, bungalow or a small family styled unit (McKee S Evermore Living Well model).

Action needs to happen now, as Housing Lin's Report in 2019 for Welsh Government indicated that their assessment estimated that there would be a significant shortfall across Wales in specialist housing and accommodation for older people by 2035.

We begin on a strong positive. This is what good will look like:

Good is when growing older does not cost the individual what it means to be a whole human being.

Good is when people are no longer “put” or “placed or “admitted” to institutions due to the lack of provisions by an archaic broken adult health and social care system.

Good is when communities across Wales are supported by agile eco-systems, innovative, cutting-edge products, services, and systems, and vibrant internal marketplaces which assure people they can sustain their lifestyles, autonomy, and dignity to the end of their lives, in their own homes, or in wherever they choose.

In 2006 the Long-term Care Revolution at Innovate UK brought together all the research and information that was needed to change the System.

Also, Karlsson in 2007 outlined the costs and future use, based on the current system, long term care and the use of Care Homes.

That evidence and thinking as well as the learning and reflection on what was tried in 2006 onwards has been available to our group as we discussed our vision and objectives this past year.

Our Key Points relevant for Wales:

- **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. They have also been stated in the consultation Rebalancing Care as well as public comments to the new Strategy on Ageing.
- 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)

- We argue that the institutional mindset is still prevalent in social care for the older adult 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, social exclusion and a lack of autonomy amongst older citizens.
- 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)

Now is the time to change the “System”. The pandemic has made existing models in this present System unsustainable. There is opportunity to build something better, or older people will fall through the net again, creating a huge pile up in NHS services as we can now see in some Health Boards already. During the pandemic the lack of easy access to GP surgeries will now present a new tsunami of increasing and more complicated need. This can still be provided in a person’s home. According to a medical discussion at an Ageing 2.0 webinar in 2021 – there is relatively little clinical treatment that cannot be provided in one’s home. We understand that the Royal College of Physicians is now focusing on a new “offer” of a higher level of domiciliary referral, treatment and advice.

Rebalancing Care, Integration and Prevention - There are now more opportunities, particularly from Regional Partnership work, for an increase in low level preventative services from the third sector, provided in local communities and in supported housing. The evidence emerging from these already shows that these new innovative services improve health and well-being. Digital Platforms that upend the economics of care, (Action for Elders Balanced Lives programme and Impact Report 2021), (The Circle in Roddam’s Radical Help 2019), the Evermore Well-being Co-operative model (McKee 2020) being developed in Manchester soon.

How we can contribute and offer Solutions

We have a strategic plan for the next five years with a focus on the evidence to underpin our mission of developing with significant and industry relevant partners a demonstration site to show what good looks like for people requiring support to live their lives in their own home to the end.

We feel that we must focus on Housing as being the vehicle to drive this innovative and tested model and in Wales because of its innovative new legislation and Senedd programme of work for citizens and communities for the future. Our decision is based on previous experience and learning of long-term care modelling.

The Demonstration site we want to plan for with relevant partners and in consultation with local citizens will contain the key components for a new eco-system of long-term care.

These are :-

Innovation policy - It is widely acknowledged that such complex systems cannot be created by government, but it is also increasingly accepted that innovation policies can play a part in nurturing their development and sustaining their vitality. The Welsh Government has plenty to consider when it comes to developing a future-oriented innovation strategy that can help Wales move up the league tables of economic and innovation performance. Nurturing an innovation ecosystem that is fit for the future will require radical, rather than incremental, developments that embrace both institutional and cultural change (Delbridge et al 2021)

Housing and architecture - Innovative, affordable, adaptable construction models, and low-cost creative retro fit, communities with dynamic and agile living environments adapt to people's changing needs.

Energy efficient systems - Integrated existing, new, and emerging supporting frameworks underpinned by zero carbon, the circular economy, and environmental sustainability goals.

Waste management systems - Domestic and clinical systems designed for easy access, affordability, and efficiency.

Advanced materials - Innovative and creative applications of existing and new materials to support activities of daily living (ADLs) and health conditions management.

Robotics and autonomous systems - A major cultural, attitudinal, and technological shift in government policy, society, and the sector, embracing the next generation of theoretical systems such as AI and machine learning, 5G, the Internet of Things (IOT), biometrics, Augmented Reality and Virtual reality, as well as quantum computing.

Health service models redesign – Upending the paternalistic medically dominant healthcare professional driven service-led models with a shift to a comprehensive consumer driven model, ranging from private, public, agency, sole trader, or any combination in any area of health care delivery. There are holistic relational models such as the “Circle” in Radical Help by Hillary Cottam (2019) and Balanced Lives (Action for Elders 2020) which show how integrated encouragement and support and self-help can improve health and well-being and support existing community health and social services.

Innovative financial models - Including models/frameworks of financial services including banks, insurance companies, large retailers, investor angels, corporates, local authorities, or any combination.

Workforce redesign – A re-design and a cultural shift in the workforce for system change, with a paradigm shift from vocational and altruistic, to entrepreneurial and disruptive social innovation. This demands new thinking, roles, quality assurance and regulatory frameworks.

Education redesign - Re-design of educational models and frameworks based on current and emerging societal trends.

To undertake this work, we are confident that this will contribute significantly to the new foundational economy in Wales.

We trust that our evidence shows that we want to take the opportunity of stimulating real action on long term care, rather than just focus on Care Home Commissioning.

We want to show that there are much better ways of supporting older adults to spend their final years.

These years would be autonomous, supported, reflective on a life lived with achievements, learning new things, enjoying activities which promote a sense of belonging, significance, security, continuity, purpose and achievement in their own home.

According to our evidence, older adults' views and our rationale we must "pivot" to change the system and one significant way which will support our action to set up and demonstrate a new eco-system is to reduce is to address commissioning for Care Homes.

As Hilary Cottam says in her book *Radical Help* "A pivot is not just another word for change. The pivot is a special kind of change that involves a new vision, a different solution and a new business model."

She argues the case saying that "it is no longer appropriate to continue with our existing systems, to persevere with programmes of efficiency or to tinker with new methods of payment that might, for a time, prop up the NHS. We must embrace the challenge because we cannot continue along the same path."

In our new reality things have changed, society has changed – we must "Pivot".

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