

Health and Social Care Committee

Meeting Venue:
Committee Room 1 – Senedd

Meeting date:
2 May 2012

Meeting time:
09:00

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



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Agenda

1. Introductions, apologies and substitutions

2. Inquiry into Residential Care for Older People – Evidence from third sector organisations and providers and on alternative models (09.00 – 11.30)

1a. Inquiry into Residential Care for Older People – Evidence from Community Housing Cymru (09.00 – 09.50) (Pages 1 – 19)

HSC(4)-13-12 paper 1 – Community Housing Cymru and Care and Repair Cymru

HSC(4)-13-12 paper 1a – Cymorth Cymru

Nick Bennett, Chief Executive, Community Housing Cymru
Richard Davies, Executive Director, Gwalia Housing Group
Kevin Hughes, Director of Care & Support, Pennaf Housing Group

1b. Inquiry into Residential Care for Older People – Evidence from Age Alliance Wales (09.50 – 10.30) (Page 20)

HSC(4)-13-12 paper 2

Rachel Lewis, Age Alliance Wales Officer
Angela Roberts, Vice Chair

BREAK 10.30 – 10.40

1c. Inquiry into Residential Care for Older People – Evidence from the Alzheimer's Society & Parkinson's UK Cymru (10.40 – 11.30) (Pages 21 – 35)

HSC(4)-13-12 paper 3 – Alzheimer's Society

Sue Phelps, Acting Director for Wales

Chris Quince, Senior Policy Officer

HSC(4)-13-12 paper 4 – Parkinson's UK Cymru

Steve Ford, Chief Executive

Val Baker, Parkinson's UK Cymru

3. Organ Donation White Paper – Follow-up briefing from Welsh Government officials (11.30 – 12.00)

4. Papers to note

4a. Letter from the Auditor General for Wales – Care and Social Services Inspectorate Wales (Pages 36 – 53)

HSC(4)-13-12 paper 5

4b. Public health implications of inadequate public toilet facilities – Letter from the Communities, Equalities and Local Government Committee (Pages 54 – 56)

HSC(4)-13-12 paper 6

4c. Letter from the Secretary of State for Wales – Convention on the rights of older people (Pages 57 – 58)

HSC(4)-13-12 paper 7

4d. Petition: P-04-359 Problems with the NHS for the Deaf (Pages 59 – 61)

HSC(4)-13-12 paper 8



Health and Social Care Committee

HSC(4)-13-12 paper 1

Inquiry into residential care for older people – Evidence from Community Housing Cymru and Care & Repair Cymru

A Response by Community Housing Cymru (CHC) and Care & Repair Cymru (CRC) to the Inquiry into Residential Care for Older People

1.0 About CHC

Community Housing Cymru (CHC) is the representative body for housing associations and community mutuels in Wales, which are all not-for profit organisations. Our members provide over 130,000 homes and related housing services across Wales. In 2010/11, our members directly employed 6,500 people and spent over £800m in the Welsh economy. Our members work closely with local government, third sector organisations and the Welsh Government to provide a range of services in communities across Wales.

Our objectives are to:

- Be the leading voice of the social housing sector.
- Promote the social housing sector in Wales.
- Promote the relief of financial hardship through the sector's provision of low cost social housing.
- Provide services, education, training, information, advice and support to members.
- Encourage and facilitate the provision, construction, improvement and management of low cost social housing by housing associations in Wales.

Our vision is to be:

- A dynamic, action-based advocate for the not-for-profit housing sector.
- A 'member centred' support provider, adding value to our members' activities by delivering the services and advice that they need in order to provide social housing, regeneration and care services.
- A knowledge-based social enterprise.



1.1 Last year CHC formed a group structure with Care & Repair Cymru and the new Centre for Regeneration Excellence Wales in order to jointly champion not-for-profit housing, care and regeneration.

2.0 About CRC

Care & Repair Cymru is the “Older People’s Housing Champion”. We are a national charitable body and actively work to ensure that all older people have homes that are safe, secure and appropriate to their needs, helping them to remain living independently in their own homes.

We provide services to the network of 22 Care & Repair Agencies across Wales. Our services to Agencies include policy information and briefing, training and networking events, co-ordination of the national database (CARIS), agency support, national PR and communications, funding allocation and performance evaluation.

Through our work, and close relationship with the 22 Agencies, we listen to the needs and desires of older people and on the national stage articulate this information to policy makers at the Welsh Government. This advocacy work helps inform thinking on older people Housing Policy and wider Health and Social Care policy which is intrinsically linked to appropriate, good quality housing.

Our Vision is:

All older people in Wales shall have warm, safe, secure homes that meet their individual needs.

Our Mission is:

Care & Repair Cymru exists to ensure that all older people have access to housing services that enable them to live in housing that meets their individual needs

3.0 Our Joint Response

3.1 Community Housing Cymru and Care & Repair Cymru commissioned a study to identify opportunities for the community housing sector to support health outcomes, particularly in meeting the needs of our ‘ageing society’. The findings of this study will be useful to inform this inquiry. Through a series of interviews and focus groups, involving professionals from both health and housing, we developed an understanding of the barriers to closer health and housing collaboration and five key practical opportunities that may be realised. The key opportunities relevant to this inquiry are:

3.2 Early discharge support in Extra Care schemes and nursing homes

Extra Care schemes and Registered Social Landlord (RSL) nursing homes located near district general hospitals may offer an effective option for high quality care to enable earlier hospital discharges of frail older people.

RSLs in at least three areas are in active talks to create or consolidate such services. Others have shown interest but conversations have not yet been held. To date, most such bookings have tended to be ad hoc and involve a handful of beds. Many RSLs are keen to explore the possibility of annualised block bookings for planning and cost reasons. However, some Health Boards are wary of block booking, wanting to retain maximum financial flexibility.

The partnership arrangement to support this form of early discharge will depend on the scheme involved. Nursing homes have existing trained healthcare capacity, and arrangements with local GPs, and there is scope to up skill staff in Extra Care schemes to some degree.

3.3 Expansion of not for profit nursing care

Three RSLs have made the strategic shift to make 'care' part of their core offer alongside housing. All three offer nursing care, aiming for a mid-market price – aiming cheaper than publicly provided services but maintaining quality standards. Such nursing homes can form the hub for a range of other services. For example, day care is offered from several homes (if the residents are content). They can also host other teams such as out of hours teams.

The opportunity for RSLs to offer nursing care across Wales seems significant, yet the move into a highly regulated service area can be daunting and many RSLs may decide to remain focused on their core housing mission. For those already committed to nursing care, and for those considering the move, clarity about the potential demand would be welcomed.

3.4 Increasing the level of care available in sheltered housing and Extra Care schemes

A number of RSLs interviewed as part of this research, particularly those who do not offer Extra Care, stated that their organisations would like to offer a wider range of care within a sheltered housing setting. They would like to be able to support residents to stay in the sheltered housing homes for as long as possible, as they become increasingly frail. Enabling sheltered housing schemes to cope with greater levels of frailty could meet people's preference for staying at home, for couples to stay together, and reduce the risk of institutionalisation in a nursing home.

Interviewees anticipate that residents of Extra Care schemes will become increasingly frail too, and reluctant to move from what are now their homes. Bringing additional (continuing) healthcare into these schemes may help prevent admissions to hospital and provide a community case for other services.

3.5 Ongoing support to enable older people to live more independently and healthier at home

Adaptations don't only ensure that older people can remain living independently in their own home for longer, they also alleviate pressure and financial strain on NHS and social services budgets. It is estimated that for every £1 spent on adapting a person's home, £7.50 is saved from health and social services budgets.

The value of investment in services that enable people to live at home for longer has been recognised by the Welsh Government, most recently in the form of a £4.77m package awarded directly to Care & Repair agencies in Wales for 2011-12.

The trusted access that Care & Repair agencies have into older people's homes can be used as a channel for other forms of support too. For example, in Monmouthshire, the Healthy Homes project has seen the initial assessment expanded to a more holistic case assessment, supporting older people to access additional care support, benefits etc. This has been highlighted as good practice within the Gwent Frailty project but, as a classic 'cinderella service', it is now at risk of losing funding. The Hospital to Home projects in Conwy and Caerphilly offer similar support, but target people before they leave hospital.

The key opportunities to support older people to live healthier at home via Care & Repair breaks down into three parts:

1. Increasing the current rapid response adaptation programme (RRAP) to meet demand;
2. Expanding RRAP to all tenure, from its focus on private housing;
3. Expanding the programme to have a wider preventative purpose, building on models such as the Monmouthshire Healthy Homes and hospital to home type schemes.

All these opportunities should save / delay NHS spend on frail older people and, more importantly, improve people's lives. A recognised challenge is that such preventative work requires investment alongside ongoing increasing demand for acute care.

4.0 Other opportunities:

4.1 Expanding and protecting telecare provision

Several RSL interviewees highlighted their interest in increasing the provision of telecare to residents across their stock. Telecare varies from scheme to scheme, but generally involves a community alarm service and regular contact by telephone. Further technology may be included such as detectors which monitor motion, falls or fire and gas risks. When activated, these technologies then trigger action by a response centre.

Some current telecare schemes are at risk because they are not statutory and are voluntarily funded by local authorities. One RSL highlighted that their scheme supports hundreds of vulnerable people in the city, both their own residents and people in private housing. As a recent stock transfer organisation,

they were pleased to inherit operational responsibility for the scheme but cannot afford to finance the scheme.

Some RSL interviewees point out that should telecare be removed, there is likely to be an immediate cost implication for the NHS – for example, owing to an increase in severity of need following a fall at home.

5.0 Specific Comments

Our comments below mainly relate to our ambition to keep older people out of an institutional care setting wherever possible, whilst acknowledging that for some older people remaining at home may not be the most appropriate or desirable option. Comments follow the headings provided for this initial response.

- **Process by which older people enter residential care and the availability and accessibility of alternative community-based services, including re-ablement services and domiciliary care.**

Whilst acknowledging that for some older people remaining at home may not be the most appropriate or desirable option, evidence suggests that most people as they age would prefer to remain living in their own home¹. Care & Repair Cymru have long been concerned about older people being placed in residential care, when it is both unnecessary and undesirable for the older person. Care & Repair work and provide services across all 22 local authority areas in Wales to maximise the independence of older people to enable them to remain living at home. This is achieved by providing tailored advice, brokering local solutions and providing and accessing grants and charitable funding that improve the home environment to meet individual needs and improve safety.

Care & Repair agencies have also supported many thousands of older people in Wales to return safely home from hospital after illness or injury (including falls and strokes) through the Rapid Response Adaptations Programme (RRAP). The programme facilitates an immediate response to specific needs by providing minor works and adaptations such as ramps and handrails, shower seats, door entry and repairs to paths and steps to enable people to return to their own homes following hospital discharge. Such adaptations can also prevent the need for admission to hospital or residential care. The programme is a fast-response initiative, with an average time of 8 days achieved in 2010/11. Older people in hospital can feel extremely vulnerable and fear returning home without support. This may

¹ Wanless D (2006) Securing Good Care for Older People: Taking a long term view. Kings Fund

lead to consideration of a residential placement. With the advice and practical support of Care & Repair, however, many people have felt confident enough to return home. During 2010/11 alone, 13,605 jobs were completed for older people through the Rapid Response Adaptations Programme, with some 9,500 preventing hospital or residential care admission and 4,200 being supported to return home from hospital.

Remaining at home is not only desirable but often cheaper than moving to a supported living environment. Care & Repair can evidence outcomes for older people that save both the older person being somewhere they don't want and need to be, and subsequently contribute a cost saving benefit to Health and Social Care. Services delivered by Care & Repair across Wales are estimated to save the NHS and social services £7.50 for every £1 spent by keeping older people out of hospital and residential care, and by helping them to return home from hospital quicker. A recent study by the Wales Audit Office of adaptation services in a Welsh Local Authority also concluded that providing a housing adaptation through a DFG delayed entry into residential care by an average of 4 years, with significant cost savings given that the average DFG cost is £7000, and an approximate 4 year cost of residential care is in the region of £110,000.

Care & Repair Cymru would welcome improved provision of community-based resources, which are tailored to the needs of older people, and advocate for greater resources to help older people remain living independently in their own homes.

New models of integrated community care would require a more 'joined up' approach, including adequate targeted local investment to ensure that home safety, wellbeing and independence are maximised through a proactive approach from statutory and third sector preventative services. Care & Repair Cymru would advocate that this integrated community service perspective should be clearly reflected in commissioning arrangements.

- **New and emerging models of care provision.**

We support increased diversity and mutual ownership of services such as domiciliary care that would help support the objective of older people remaining living in their own homes and communities.

- **Balance of public and independent sector provision, and alternative funding, management, and ownership models, such as those offered by the cooperative, mutual sector and third sector, and Registered Social Landlords.**

Stronger mutual, co-operative, third sector and RSL involvement in residential care and domiciliary care would be desirable. Care & Repair Cymru are happy to be involved in partnership arrangements that



facilitate more efficient access and exit into and out of residential care, with a strong desire to help older people move to the accommodation and setting they prefer as quickly as possible.

6.0 Conclusion

We appreciate the need for a rational approach to preventing ill health in older people and supporting their independence. This can mean providing a range of holistic services to keep people active and involved in their communities, rather than having acute treatment or residential care.

Registered Social Landlords have shown themselves to be a new and emerging model of care provision who can aid in meeting the future needs of the ageing population.

CHC are CRC would welcome involvement in future discussion in this area.

CHC & CRC
December 2011

Health and Social Care Committee

HSC(4)-13-12 paper 1a

Inquiry into residential care for older people- Evidence from Cymorth Cymru

Cymorth Cymru Evidence to: Health and Social Care Committee

Inquiry into residential care for older people

12/12/2011

Background

Cymorth Cymru is the representative body for providers of housing-related support, homelessness and supported living services in Wales. We have over 120 organisational members who all work to assist people who are vulnerable, isolated or experiencing housing crisis, including:

- people who are homeless, or at risk of homelessness
- families fleeing domestic abuse
- people dealing with mental or physical health problems, or learning disabilities
- people with alcohol or drug problems
- refugees and people seeking asylum
- care leavers and other vulnerable young people, and
- older people in need of support

This list isn't exhaustive, and individuals may often face a range of challenges that make it difficult for them to find or maintain a stable home and build the sort of lives we all aspire to.

Cymorth Cymru's members help people address these issues, supporting them in finding both emergency accommodation and long-term, secure homes, where they may fulfil their potential and build happy and fulfilling lives.

We have three overarching objectives:

- To improve the links between policy and practice by ensuring that those working in frontline service delivery understand and are influenced by the wider policy context, and those working in policy development understand and are influenced by the experiences and knowledge of those working on the ground.
- To ensure that the sector maximises its contribution to the lives of citizens and the communities in which they live by helping to build and develop the sector's capacity and professionalism.
- To increase public understanding and support for the sector and the work it does in helping people build the lives they aspire to within the community.

Acronyms used in this response:

HWC – Housing with care

BASW – British Association of Social Workers

RSL – Registered Social Landlord

CSSIW – Care and Social Services Inspectorate Wales

LD – learning disabilities

LGB&T – Lesbian, Gay, Bisexual & Transgender

Overview of evidence

It is understandable that reviews or inquiries into residential care tend to focus on issues relevant to mainstream care provision. Cymorth Cymru is particularly grateful to the Committee for not limiting its remit in this way and for giving us the opportunity to highlight issues regarding the care needs of more marginalised older people and also to draw attention to alternative models of housing with care (HWC) provision that exist which can help meet the future care needs of older people in Wales.

In drafting this response we are grateful to our members working within housing associations, third sector organisations and local authorities for their input.

We have also liaised with partner organisations and would like to take this opportunity to endorse the evidence provided by Community Housing Cymru.

Our evidence is presented in the following format:

- General comments
- Responses to the Inquiry's specific points
- Summary of our key points

General comments

Cymorth Cymru's vision is that all people in Wales are able to build and maintain happy, successful lives that maximise their independence within welcoming and supportive communities. With an ageing population, many of our members who work with older people are seeing and anticipating further increases in demand for services. Some members are specialists working in housing, support and care for older people, and others specialise in particular services that we are seeing increasing numbers of older people accessing such as those responding to homelessness, drug and alcohol issues, domestic abuse, learning disabilities/autistic spectrum disorders, mental ill-health and services working with people with a history of offending/prison leavers.

As well as outlining the issues faced by older people in relation to residential care, our evidence will pay particular attention to the experiences of marginalised older people and the future provision of residential care to meet the changing needs of older people in Wales.

Our main points are:

- We need to see a move away from care provision that is driven by profit in favour of ethically run, mutual based models. Although we recognise the advantages of some private sector providers, third sector organisations have proved to be a new and emerging model of care provision and can aid in meeting the future needs of the ageing population and, as such, should be further developed.
- More choice and control is needed so that individuals can access the right type of housing with care that best meets their needs. Provision such as Extra Care schemes and care at home needs to be a real option for individuals. Better use should be made of assistive technology to help people meet their health and care needs without having to move or lose their home.

- A characteristic of more marginalised older people is that they have difficulties in engaging with statutory services. This is often due to both a lack of appropriate services and a lack of willingness of health and social care professionals to work with people with complex needs. Service provision needs to take account of the needs of more marginalised older people and services need to be tailored appropriately.

Responses to the Inquiry's specific terms of reference

Terms of reference 1 - The process by which older people enter residential care and the availability and accessibility of alternative community-based services, including reablement services and domiciliary care.

Feedback from our members indicates that there is great disparity around the range of provision offered to an individual. Access to different types of provision is largely determined by the local knowledge of the social worker or person advising as to the range of services that are offered. As a result, the offer of provision within a locality can differ vastly.

As a direct result of the lack of knowledge of different types of provision available, many individuals have found themselves entering residential care settings when more independent forms of housing with care would have been more suited to their needs and helped them to maximise their independence for longer. We are aware of a number of instances where individuals have been inappropriately placed in a residential care setting due to their social worker not being aware of other more suitable options. In the current economic climate, this issue is even more pertinent now as we do not know how many other people are living in inappropriate situations which are both expensive for the public purse and limit the individual's independence unnecessarily.

Evidence shows that supporting a person to remain independent has an important role to play in the health and wellbeing of an individual – this reduces the burden and cost to other areas of spending such as the Welsh NHS. There needs to be further work into determining how many people in Wales have been inappropriately placed and we suggest that the Welsh Government (WG) commission research into the range of options that individuals are made aware of in order to fully maximise the return on public spend.

We would also endorse the recent study carried out by the Care Council for Wales around person centred planning which resulted in guidance to the sector. This guidance points to the positive outcomes of taking a structured person centred approach in terms of choice and wider information to

inform better care and support. The guidance is available at:
<http://www.ccwales.org.uk/development-and-innovation/adult-workforce/older-people-workforce>.

Terms of reference 2 – The capacity of the residential care sector to meet the demand for services from older people in terms of staffing resources, including the skills mix of staff and their access to training, and the number of places and facilities, and resource level.

In light of the recent Winterbourne View case, there are serious concerns around staffing skills and levels within residential care. The use of poorly paid and under-qualified care staff is an ongoing cause for concern as highlighted by a recent BASW survey in which 81% of social workers stated having come across abuse within adult residential care homes across the UK.¹

Poor levels of pay for frontline workers in older persons services, in comparison to equivalent positions in adult services, does not allow care services to attract and retain ambitious staff. As a result, the skill mix of staff tends to focus on delivering a task focussed rather than an outcome focussed service. This results in staff doing things for, rather than with, the client.

One of the barriers often faced by organisations in relation to staff training can be ensuring that there is a comprehensive training plan in place for all of their staff when places on approved training courses are limited. In some instances, local authorities insist on providing their own training courses of which usually only 2 places are allowed on a quarterly basis. This can make it difficult for provider organisation to meet their statutory requirements as they are unable to gain access to enough local authority provided training courses and therefore struggle to adequately train the whole of their workforce.

Terms of reference 3 – The quality of residential care services and the experiences of service users and their families; the effectiveness of services at meeting the diversity of need amongst older people; and the management of care home closures.

Residential care services vary widely across Wales in the level of the quality of the service that they provide. We support the intention of the Care and Social Services Inspectorate Wales (CSSIW) to place more focus on the experiences of service users and their families. Other initiatives such as CareChecker in Wales (www.carechecker.co.uk) are playing a crucial role in raising the standards of care provision through training volunteers – made by of people receiving care, their relatives, visiting

¹ British Association of Social Workers Survey - <http://www.basw.co.uk/media/shocking-state-of-care-for-vulnerable-adults-revealed/>

professionals, or local community members – to make judgements about the quality of the service being provided. Central to their approach is judging how committed a service is to person centred working.

Care home closures cause much distress, especially for vulnerable people and we strongly feel that a more robust oversight of finances would prevent closures from happening as a surprise and would therefore limit the distress caused.

For more marginalised older people who often experience greater discrimination and isolation and that sometimes don't enjoy the support or understanding of the general public (such as people with offending behaviour and/or drug/alcohol issues, those requiring gender specific care, LGB&T people, or ethnic minority groups), mainstream residential care services are often unsuitable for a variety of reasons. For older people with alcohol dependency issues, residential care can be an unattractive option due to the financial implications accompanying it – for example, some individuals may not want to give up drinking but would not be able to afford to continue if they moved to a residential care setting. The mix of residents in mainstream residential care often acts as a further barrier as many individuals fear that their lifestyle may be acceptable to other residents.

It is often the case that the needs of more marginalised older people – such as those with substance misuse issues – are often not recognised and, as such, there needs to be greater awareness within the care sector of such issues as Korsakoff's syndrome – a brain disorder usually associated with heavy alcohol consumption over a long period which is not always manifest due to the confabulations (inventing stories to fill the gaps in memory) that it causes – in order to better tailor service provision.

As more and more people with learning disabilities (LD) are living longer, they are increasingly suffering from age related conditions such as Dementia. A recent report² in England has highlighted the need for a “significant improvement” in the training of nursing staff in relation to issues around caring for those with Dementia, adding that nursing staff need more support, training and recognition for the difficult job they do. In addition to this, mainstream residential care is often unsuitable given that staff are rarely skilled in relation to LD issues. There can also be an age imbalance it is the case that, with some forms of LD, individuals may suffer from Dementia at a relatively young age and would therefore be wholly unsuited to a mainstream residential care setting.

In order to meet this diversity of need both now and in the future, there needs to be improvement in the quality and spread of specialist care services in Wales that are underpinned by an understanding of the specific needs of socially excluded older people. We would also like to see national strategy and

² Report of the National Audit of Dementia Care in General Hospitals 2011

policy development better recognise and meet the needs of socially excluded, marginalised and vulnerable older people.

Terms of reference 4 - The effectiveness of the regulation and inspection arrangements for residential care, including the scope for increased scrutiny of service providers' financial viability.

We are keen to support the move to a more outcomes driven approach to regulation and inspection arrangements for residential care as such an approach can make services more client focused and needs led by identifying what works well, and what could be improved.

It is felt that there is not enough scrutiny on the quality of the service provided, such as care planning and whether clients are treated with respect and dignity. There is no method that accurately captures the viewpoints that families and clients hold towards the service. We would like to stress the importance of actually speaking with service users in relation to inspection as opposed to simply focusing on what may be contained within paperwork. In this way, inspections can gain a fuller picture of the service provided and better identify any need for improvement.

In addition, the quality of inspection reporting can be poor and not be of a high enough standard. The same inspector may visit a service on several occasions and build up personal relationships with staff, which can impact on the outcome of the inspection report and produce inconsistencies. A consideration towards alternative methods of inspection and regulation, such as mystery shopping, could help alleviate inconsistencies in reporting and result in reviews that reflect experiences more accurately.

In light of the Southern Cross case, serious concerns around the financial viability of other residential care homes that are driven primarily by profit still remain. Given that inspections do not consider whether services are applying their resources flexibly, there is currently no way of knowing whether service providers are experiencing financial difficulty.

We would urge the WG to consider much more robust regulation in terms of the financial information that organisations are required to provide on an annual basis. Third sector organisations are required to conform to 'open book accounting' as in the sense that registration with the Charity Commission³ makes their accounts open to public scrutiny and it is essential for any organisation that works with vulnerable people to be accountable in the same way.

³ <http://www.charitycommission.gov.uk/publications/cc15.aspx>

Terms of reference 5 – New and emerging models of care provision

In order to fully meet the care and support needs of older people in Wales, we strongly believe that a range of service provision is needed as opposed to a 'one size fits all' type of approach. Where as good residential care services are suited to some individuals, more independent models of care are needed to satisfy others. Having your own home gives you a level of independence that it is impossible to achieve in other, more institutional settings.

Extra Care

For this reason, many people are choosing Extra Care as their preferred option of dealing with their increasing care needs as it allows individuals to have their own tenancy or 'own front door', allowing them the control to dictate who does or does not enter their home at any given time. Also, for older people in receipt of benefits, it gives them a higher income which in itself increases independence.

Extra Care are one type of housing with care provision that offer a model of housing, support and care provision that promotes independence and provides older people with a home for the rest of their lives. The ethos behind Extra Care is that it enables people to live fuller, healthier lives with the emphasis on improving quality of life rather than only providing a safe, caring environment as offered by traditional models of residential care. Extra Care housing is popular with people whose disabilities, frailty or health needs make ordinary housing unsuitable but who do not need or want to move to long term care (residential or nursing homes). Although older people make up the majority of users of extra care, people with disabilities that are not age related are increasingly making use of this type of housing. Extra care provision comes in a huge variety of forms and may be described in different ways, for example 'very sheltered housing', 'housing with care', 'retirement communities' or 'villages'.

Whilst a concerted effort is made to make Extra Care a home for life, there are many cases where individuals are forced to move into more dependant forms of provision when their care needs increase to a level where funding is no longer available to meet their needs within an Extra Care setting. For instance, if the needs of an individual increase considerably on an intermittent basis then such occurrences can be dealt with but where this is ongoing it creates difficulties. Therefore, limitations are sometimes caused by the pre-conceived level of need that comes with the block contact of funding. It appears that that model itself is able to meet increasing and decreasing support, care and health needs but current funding arrangements may be limiting this flexibility.

We suggest that further work needs to be done to consider how financial arrangements could be configured to allow greater flexibility in terms of what is offered to residents to ensure the changing range of needs are met over their lifetime.

Increasingly Extra Care housing is recognised as an essential component of joint commissioning by health and social care with Extra care now being used for reablement as well as longer term housing. Extra Care schemes and also Registered Social Landlord (RSL) nursing homes located near district general hospital may offer an effective option for high quality care to enable earlier hospital discharges of frail older people. The partnership arrangement to support this form of early discharge will depend on the scheme involved but despite the growing need to ease demand for Secondary Care services, most arrangements of this type tend to be informal arrangements on a small scale. Many RSLs are keen to explore the possibility of annualised block bookings for planning and cost reasons but some Health Boards are wary of committing to such arrangements in order to retain maximum financial flexibility.

There is generally a lot of support for this approach as it allows individuals to regain the confidence to live independently. We suggest that the WG supports this approach by rolling out the current good practice in this area across Wales.

Care at home

An increasing number of people are choosing to remain in their own home and wish to receive care and support within this setting. Therefore, many providers of sheltered accommodation who provide housing-related support to their tenants would also like to offer care services to support their tenants in general needs housing to remain in their own home for as long as possible. Bringing additional (continuing) healthcare into these schemes may help prevent admissions to hospital and provide a community base for other services.

A key element of being able to remain and receive care at home is the availability of adaptations. Adaptations enable people to stay in their own homes and in their own communities with their existing support networks and also support peoples' rights to make a real choice about where they live and can avoid the trauma and cost of more institutional provision types. They also produce a range of lasting positive effects such as improved dignity, privacy, independence, health (physical and mental) and social inclusion.

As such, it is estimated that for every £1 spent on adapting a person's home, £7.50 is saved from health and social services budgets. The value of investment in services that enable people to live at home longer has been recognised by the WG, most recently in the form of a £4.77 million package awarded directly to Care & Repair agencies in Wales for 2011-12. However, as Care & Repair services are focused on private housing, we support CHC's call for its expansion to all tenure.

As with housing adaptations, the demand for telecare and telehealth provision is increasing as both technologies offer the potential to reduce visits by patients to health care providers (and vice versa), facilitate more localised health care and services, providing more timely diagnosis and intervention, and even reductions in costs.

Telecare uses a combination of alarms, sensors and other equipment to help people live more independently by monitoring for changes and warning the people themselves or raising an alert at a control centre. (Examples of telecare devices include personal alarms, fall detectors, temperature extremes sensors, carbon monoxide detectors, flood detectors and gas detectors). Telehealth covers the remote monitoring of physiological data e.g. temperature and blood pressure that can be used by health professionals for diagnosis or disease management. (Examples of telehealth devices include blood pressure monitors, pulse oximeters, spirometers, weighing scales and blood glucometers). Telehealth also covers the use of information and communication technology for remote consultation between health professionals or between a health professional and a patient e.g. providing health advice by telephone, videoconferencing to discuss a diagnosis or capturing and sending images for diagnosis).

We envisage technology such as the above being used more and more to help people meet their health and care needs without having to move or lose their home. Despite the benefits brought by assistive technologies, some schemes in Wales are currently at risk as they are not statutory funded. Should these schemes be removed, we anticipate an immediate cost implication for the NHS – for example, owing to an increase in severity of need following a fall at home.

It would seem that there are real savings to be made from further investment in this area as both a preventative measure and in responding to immediate need. Given the current strains on public spending, we suggest that more attention is given to assistive technology as a compelling method of delivering care at home.

Term of reference 6 - The balance of public and independent sector provision, and alternative funding, management, and ownership models, such as those offered by the cooperative, mutual sector and third sector, and Registered Social Landlords.

Increasing numbers of residential care homes for adults are being privatised despite the growing opinion that care homes should not be run for private profit. In contest of this, many RSLs in Wales are making the strategic shift to include 'care' as part of their core offer alongside the spectrum of accommodation that they provide. RSL run nursing care homes aim to deliver mid-market price care services whilst maintaining quality standards. Such nursing homes can also become a hub for a range of other services such as day care or hosting other out of hours teams.

Support for ethically run, not for profit care provision is gathering pace in Wales as they purport to be a better use of public (and services users') money given that all income is spent on care and support and any surplus is reinvested in the organisation. They are also service driven by values and principles and crucially not by profit – therefore delivering higher standards of care and dignity to those using their services. The third sector is also able to work together more effectively and flexibly to deliver joined up services, provide extensive infrastructure and provide quality services across the continuum of care. Organisations' services are normally rooted in the communities which they serve, providing local holistic and outcome focussed services for people.

As such, the opportunity for Third Sector run nursing care across Wales seems significant; yet the move into a highly regulated service area can be daunting. For those already committed to nursing care, and for those considering the move, clarity about the potential demand would be welcomed.

Cooperative Models of Care

Cymorth Cymru recently hosted a master class with Mutual Advantage who have carried out a number of projects looking at how cooperative models of care can be used to provide better services and more control to older people and people with disabilities. There is much to learn from such initiatives and we would suggest that the principles and approach could be adapted to the Welsh context:

http://www.mutual-advantage.co.uk/CMS/uploads/CoopsUK_Care_Report.pdf

However, to achieve this in Wales the citizen directed support agenda needs to be taken forward. We would like to see the WG take advantage of this opportunity to effectively combine cooperative models of care and personalisation in order to transform care provision in Wales.

Summary of key points

In summary, reviews or inquiries into care provision understandably tend to focus on the needs of the general population and we welcome the invitation to contribute to the Inquiry so that we can highlight the specific issues that our most vulnerable citizens experience in accessing residential care.

In relation to residential care for general needs older people, we feel that improvements can be made through:

- Better awareness of the range of care provision available to individuals by social workers/person advising;
- Further work into determining how many people in Wales have been inappropriately placed in residential care;

- More robust regulation in terms of the financial information that organisations are required to provide;
- The development of alternative models of care such as Extra Care and increased availability of receiving care at home;
- The expansion of Care & Repair services to all tenures;
- More investment in assistive technologies
- The development of ethically run, not for profit and cooperative care provision.

Although it is important to challenge the prevalence of negative images of ageing, it's equally important to recognise that for some marginalised older people, ageing can be far from a positive experience. In order to better meet the care needs of more socially excluded older people in Wales, we would like to see:

- Increased availability and better quality staff training (especially in relation to understanding the more complex needs of marginalised individuals) and;
- Increased range of service provision to cater for the needs of more marginalised older people.

Taking a broad approach to this issue and exploiting all possible vehicles for meeting the growing need for a range of care provision is, we believe, the best way forward in the current climate and as part of that we would suggest further exploration of what cooperative models of housing with support/care could deliver. We would like to assist the WG in taking this forward and would be more than happy to arrange visits to new models of Third Sector care provision in Wales.

Once again, thank you for the opportunity to give evidence. In the current economic climate organisations working with people facing a range of challenges and conditions are worried that without a lead from the Welsh Government, those with the most acute care needs will be forgotten and face lives spent in institutions or on the streets when they could and should be able to achieve rewarding, independent lives within the community.

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Agenda Item 2b

Health and Social Care Committee

HSC(4)-13-12 paper 2

Inquiry into residential care for older people - Evidence from Age Alliance Wales

Age Alliance Wales is the alliance of national voluntary organisations working, either exclusively or primarily, with and for older people in Wales.

The following organisations, who are members of Age Alliance Wales, provided written evidence in response to the Committee's consultation on residential care for older people:

Age Cymru (RC 41)

Alzheimer's Society (RC 50)

Care and Repair Cymru (RC 45)

Crossroads Care (RC 27)

RNIB (RC 54)

Action on Hearing Loss (RC 54)

WRVS (RC 21)

The responses have been published on the Committee's website, and can be accessed through the following link:

<http://www.senedd.assemblywales.org/mgIssueHistoryHome.aspx?Ild=2222>

Committee Service

Alzheimer's Society

Health and Social Care Committee

HSC(4)-13-12 paper 3

Inquiry into residential care for older people – Evidence from the Alzheimer's Society

National Assembly for Wales
Inquiry into residential care for
older people
16 December 2011

1. About Alzheimer's Society

Alzheimer's Society is the UK's leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

2. About dementia

There are over 42,000 people with dementia in Wales and this is forecast to increase to 56,000 by 2021.¹ There are currently 750,000 people with dementia living in the UK, over one-third of these people live in residential care.² Two-thirds of people in residential care services are living with dementia. The role of care homes has now become the provision of late stage dementia care and the primary task of the care home sector is providing good quality care to people living with dementia. On average each council in Wales spends 37% of their budgets on residential care for older people.³

Dementia currently costs the UK £20 billion per annum. This is an average of £25,472 per person with late onset dementia. By 2018 dementia will cost the UK £27 billion per annum if nothing is done to improve the cost-effectiveness of dementia services.⁴ The majority of the costs of dementia care come from institutional care, such as residential care and hospital care.

3. Policy context

In Wales, the Health Minister has identified dementia as an area for action. The Welsh Assembly Government has launched a National Dementia Vision for Wales and published four Dementia Action Plans, which includes objectives to improve the quality of general hospital care for people with dementia, reduce their length of stay in hospital and to develop more closely integrated services.

In the past, services for people with dementia in Wales have often been inadequate and poorly funded. A decade-long review of social services in Wales found gaps in the provision of services for people with dementia, from intensive specialist care through to day care and respite.⁵ The availability of

¹ Tesco, Alzheimer's Society and Alzheimer's Scotland (2011) Mapping the Dementia Gap – study produced by Tesco, Alzheimer's Society and Alzheimer's Scotland

² Alzheimer's Society (2007) Dementia UK, a report to the Alzheimer's Society by King's College London and the London School of Economics

³ SSIA, (2011), Better Support at Lower Cost: Improving efficiency and effectiveness in services for older people in Wales

⁴ Alzheimer's Society (2007) Dementia UK, a report to the Alzheimer's Society by King's College London and the London School of Economics

⁵ Care and Social Services Inspectorate Wales and the Wales Audit Office (2009) Reviewing

services in the community is vital to prevent inappropriate admissions to hospitals and care homes. Better coordination of care, greater rates of diagnosis and earlier intervention are essential to improving the quality of life of people with dementia in Wales. There is much that can be done to improve dementia care, as laid out in the Dementia Action Plans. Dementia is a public policy priority and the implementation of this guidance must be fully integrated with work to improve dementia care.

The framework for action, 'Sustainable Social Services for Wales', takes account of the fact that for some people a care home is the right answer, but care and support services must work within a proactive model. This framework also recognises the challenges in providing services to an increasing number of people with dementia.

The forthcoming Social Services Bill will need to meet the needs of people with dementia and their carers or it will fail a core group of service users.

4. The process by which people with dementia enter residential care

Often people with dementia enter residential care as a result of insufficient support to remain independent in their own home. The importance of the support that carers provide is demonstrated by research which found living with a carer means that people with dementia are 20 times less likely to enter a care home.⁶ However, good quality community services are also important in providing care as they can delay entry into residential care. Inadequate care services in the home mean that a person with dementia will often enter a care home at a time of crisis.

Alzheimer's Society Home from Home (2008) report found that a significant number of carers said that it became clear the care home could not meet the individuals' needs soon after admission. This highlights the need for thorough pre-admission assessment to ensure the place of discharge can meet the individuals' needs. This can be neglected, especially when there is pressure to find a care home place quickly for that individual.

Delayed transfers of care from hospitals often mean people with dementia enter residential care. The National Audit Office (2007) has highlighted that whilst there has been significant progress in reducing the number of older patients whose discharge from hospital is delayed, people with dementia are estimated to constitute one half of people who remain in hospital unnecessarily.⁷ The longer people with dementia are in hospital, the worse the effect on their symptoms of the dementia and the individual's physical health and discharge to a care home becomes more likely.⁸ Over a third of

Social Services in Wales 1998-2008. Cardiff.

⁶ Banerjee S, Murray J et al, (2003) Predictors of institutionalisation in older people with dementia

⁷ National Audit Office (2007). Improving services and support for people with dementia. National Audit Office: London.

⁸ Alzheimer's Society (2009) Counting the cost: caring for people with dementia on hospital wards. Alzheimer's Society: London.

people with dementia who go into hospital from their own homes are discharged to a care home setting.⁹

5. Availability of alternative community-based services

The SSIA report, 'Better Support at Lower Cost', states that some councils are beginning to look at more community-based services for people with dementia and some councils include dementia care as part of their reablement services helping people manage their conditions. One or two councils have established specialist dementia domiciliary care teams that are specifically trained to help people with the condition manage at home. The statistics show that some councils support around 10% of older people to live in the community, whereas others support less than 6%. This shows that the availability of alternative community-based services across Wales is inconsistent. Some areas have good services, whereas others have none at all.

The example of Monmouthshire County Council used in the afore-mentioned report shows that it is possible to reduce the use of residential services and increase the number of people supported to live at home. The future of their success depends on developing reablement services, remodelling residential care and building further working partnerships with other bodies.

The report also notes that Welsh councils' biggest challenge is how to change the prevailing culture within adult social care. The old system has created a paternalistic and protective set of services based on institutions and has built dependency both from service users and staff. The report goes on to say that building a care and support system that focuses on keeping older people out of residential care and using reablement models of care may assist not only in achieving better outcomes for individuals but also in reducing demand for services that may have otherwise occurred.

6. Quality of residential care services

Despite the hard work of many care staff and care providers there are many thousands of people who cannot access the quality care and support that they need to have a good quality of life. The latest report from Age UK¹⁰ and others show that the system is not simply in need of repair but is fundamentally broken. Two thirds of people living in care homes are people with dementia. Therefore, the provision of care and support in residential services has to respond to the care and support needs of people living with dementia and their family carers.

Alzheimer's Society recently carried out research into the quality of care for people with dementia. One carer highlighted the importance of the consistency of care. In order for the person with dementia to build trust with staff, there should only be a small number of carers looking after them.

⁹ *ibid*

¹⁰ Age UK (2010) *Care in Crisis: causes and solutions*. Age UK. London

In the Home from Home report, inactivity was identified a major issue for carers. An Alzheimer's Society survey found that the typical person in a home spent only two minutes interacting with staff and other residents over a six-hour period of observation, excluding time spent on care tasks.

The same report also identified poor standards of personal care in some homes. Carers found this to be particularly upsetting and cited that their relative would be unhappy that their standards of personal hygiene were not met. In its recent research one carer told the Society of basic nursing care standards not being met in a range of nursing homes, for example a soiled commode, a catheter with mould growing in it and a blocked catheter leading to hospital admission. Other carers told of examples of residents being harmed for example by mistakes in drug administration made and covered up and of a serious sexual assault by another resident.

Activities and engagement

Inactivity can lead to loss of physical function, social isolation, behavioural symptoms and a poor quality of life. In the Home from Home report, Alzheimer's Society found out that activity and engagement is an unmet need. Research shows that residents with more severe cognitive impairment had their physical needs attend to, but little time was left for social, emotional or occupational needs.¹¹

Access to gardens can be beneficial to people with dementia living in care homes. For example, they can continue with their gardening hobby or benefit from taking exercise or being in the fresh air. Evidence from carers of people with more severe dementia often report that the gardens were off limits to their friend or relative as there were no care staff to accompany them to the garden. Nevertheless, many care staff consider having more time to spend chatting and interacting with residents would bring more job satisfaction.

As the Dementia Action Plan states, the CSSIW will inspect care home on their availability of meaningful activities for people with dementia. Ensuring that people's personal preferences are taken into account, this measure should improve people's experiences of care homes.

Involvement of friends and families

A majority of carers still want to be involved in care of their relative after they have moved into a care home as this helps to maintain good relationships and can be linked to quality of life and engagement in activity. In the Home from Home report, nearly a third of carers said they did not get enough information and updates from the home about their relative or friend's medical condition and treatment. In fact, carers often face an uphill struggle to find out what happened after seeing their loved one with bruises.

¹¹ Ballard et al (2002) in Alzheimer's Society (2008), Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes

In addition, a number of carers feel unable to make complaints as they fear that this would make life even more difficult for their friend or relative. Some carers complain after their relative has moved to another home or has died.

Conversely, many carers see relatives groups as an important resource in improving services in the care home. They also provide a forum for interaction between carers and give them opportunities to compare experiences.

Management of care home closures

Local authorities have a duty to provide care home places for people in need of them, meaning, should a care home close, residents have to be found an alternative place in another care home. If there is not capacity in the local area, people may be moved some distance to an alternative care home. However, human rights law means that people cannot be forced to move care homes where there is significant risk to their health; this applies even when care homes face closure.

There is little research evidence on moving people with dementia from one care home to another and the impact this can have on their health and wellbeing. However, the Society knows such moves can be unsettling and confusing for people with dementia and risk disrupting continuity of care. Staff in a person's new care home may not understand their preferences and needs and even in the best cases, will take time to deliver quality care.

7. Capacity of the residential care sector to meet the needs of people with dementia, in terms of staffing resources

According to the Alzheimer's Society report Home from Home, carers think that the staff team is the key to a dementia care home. In fact, according to the report, care managers believe that the biggest challenges they face relate to developing a staff team with the right attributes and skills and keeping them motivated.

Good induction and ongoing training are needed to develop a good staff team and this has benefits for both staff and residents. Research from Alzheimer's Society and other organisations shows that dementia care training can reduce staff turnover and increase job satisfaction.¹² Training can help staff to overcome some of the challenges they face while supporting people with dementia. The Welsh Assembly Government's commitment to improving training is welcome. This will help to prevent staff sickness and a high staff turnover.

People with dementia dominate the care home population; therefore, the impact of dementia can be felt in most care homes. In a report from Alzheimer's Society, staff in care homes found communication with people with dementia can be particularly challenging. People with dementia communicate through behaviour that may be seen as challenging. As a

¹² NICE / SCIE (2007), Dementia: the NICE SCIE guideline on supporting people with dementia and their carers in health and social care, London

result, people with dementia are increasingly vulnerable to exclusion and isolation. They may even be neglected and ignored if care staff do not have the skills to communicate effectively.

As pointed out in the National Dementia Vision for Wales, some people with dementia will only be able to understand or communicate in their first language as their illness progresses. Therefore, the need for bilingual provision of services may be a necessity for someone diagnosed with dementia.

The National Dementia Vision for Wales states that people with dementia have the right to be treated with dignity and respect. However, Alzheimer's Society has found examples of staff showing a lack of respect to people with dementia, for example by making fun of residents or talking about them in a disparaging way. Some carers reported that residents were treated like objects while personal care tasks were carried out.

Staff working in care homes are accorded a low status. Therefore, it is difficult to attract staff, which is a major issue. The status given to care home staff is also reflected in the level of pay and rewards. Working with people with dementia can be emotionally and physically demanding and there are other jobs which are less stressful and pay a similar wage.

8. Regulation and inspection arrangements and scrutiny of service providers' financial viability

Better market intelligence and improved information sharing can highlight any potential problems before they arise. However, Alzheimer's Society would like to see information publicly available in accessible formats. This is so that people with dementia and carers can make an informed decision when choosing a care home. Improved transparency is key to detecting providers at risk of failure. Therefore, it should be mandatory for providers to publish audited accounts and enhanced information.

In the current financial climate, local authorities may not have the resources to intervene and manage a situation to avoid the failure of a provider. There must be measures in place for central government to take control of a situation if a single local authority is not able to do so.

The role of CSSIW inspectors is central to improving dementia care. Regular inspections could help to detect providers who may be at risk of failure and inspectors could feed this information back to the relevant body.

9. Recommendations

- Ensure good quality community services are available to delay entry into residential care.
- Develop specialist assessment procedures which are systematic and standardised in approach.

- Introduce a thorough pre-admission process to ensure the person with dementia finds a residential service which best meets the individual's needs.
- Monitor the availability of meaningful activities for people with dementia through CSSIW Inspections.
- Encourage the involvement of relatives and carers in the care of the person with dementia.
- Introduce mandatory training in dementia care for all care home staff.
- Introduce systems for sharing good practice among care homes.
- Recognise the need for bilingual provision of services for some people with dementia.

For more information, please contact:

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Health and Social Care Committee

HSC(4)-13-12 paper 4

Inquiry into residential care for older people – Evidence from Parkinson's UK Cymru

Parkinson's UK's response to National Assembly for Wales' health and social care committee inquiry into residential care for older people

Parkinson's UK welcomes the opportunity to provide input to the inquiry into residential care for older people. Our submission comprises information provided by people with Parkinson's, and staff members. It includes a separate submission from a relative – *please see appendix at the end*. Our responses relate primarily to the first three points of the inquiry, with one relating to the fourth point on regulation and inspection.

- 1. Process by which older people enter residential care and availability and accessibility of alternative community-based services**
- 2. Capacity of residential care sector to meet the demand for services from older people in terms of staffing resources**
- 3. Quality of residential care services and the experiences of service users and their families; the effectiveness of services at meeting the diversity of needs amongst older people.**
- 4. effectiveness of regulation and inspection arrangements**

- There is a lack of quality and practical information and support on tap for people and their families on the cusp of making the transition from their familial home to a residential/nursing one. Self funders are often given even less information and support than others. If they're lucky, they or a family member may be given a written list of local care homes, but we are aware of someone who was told by social services that such a list exists and that was it – no further help was provided. Many people don't have information or help in claiming any benefits they are entitled to.
- Little or no thought is given to the input a partner/carer could have in assisting the care package e.g. psychological and emotional support. e.g. how far to travel for visiting etc
- Counselling and support for carers to deal with feelings of guilt and change of lifestyle is needed.
- There is poor monitoring of a person's well being/progression of condition to aid provision of quality care and cases for continuing health care.
- There are poor levels of cleanliness in many homes
- There is a lack of consistency of staff – probably due to low pay, poor working terms and conditions, long shifts and little chance of promotion.

- There is a lack of awareness and understanding of Parkinson's amongst staff, particularly how the condition varies from day to day.
- In one residential home, feedback from partners/carers indicated a general caring attitude by staff, but a lack of attention to detail and a great variation in care according to which carers were on duty. They often seemed to be short staffed and there were issues with one client who did not appear to be properly cared for in terms of personal hygiene
- Those homes that are well run and put the resident first are usually managed by individuals with a strong sense of duty to their service users and their families and have an open door policy. A very positive step used by some is to include family members on interview panels.
- We recommend that spot check inspections should be the norm in order to gain a true picture of how homes are being run and to ensure consistency of good practice.

The following is an extract from our policy statement on [Funding and delivering long term care](#), developed with people with Parkinson's. It provides further information and evidence on some of the issues being looked at by the inquiry:

Delivering care

- Social care must be clear and easy to understand, access and use, free of stigma, with a national system of assessment and eligibility in each country.
- Local authorities and local health bodies must work together to deliver joined-up support for people with Parkinson's.
- The contribution of carers should be properly recognised, with appropriate support, including respite, provided to those who need it.
- Services should be flexible and built around the needs of the individual, who must have the ability to choose and control the type of support provided and how it is delivered.
- Encouraging preventative measures should be central to any system and proper account must be taken of the real cost of not providing services.
- A long term approach must be taken to assessing need and providing support, recognising that Parkinson's is long term fluctuating condition.
- Information about what support may be available and how to get it must be accessible to all, including those funding their own care, with advocacy and brokerage for those that need these services.
- Assessments should explore ways to ensure independence and avoid unnecessary admission to residential care and include self-management where appropriate.
- National standards for commissioners and providers must be in place to ensure high quality care services, and performance against these standards should be monitored, regulated and enforced against where people's experiences of care are poor.
- People should be safeguarded from abuse and neglect and have their dignity protected, with clear complaints and appeals procedures in place.
- Staff in health and social care settings must have information about Parkinson's and services must be appropriate for people with long term, fluctuating conditions.

- There should be a national approach to adult social care workforce, to ensure they have an equal status to the healthcare workforce and meet national standards of care.

Why we believe this

Parkinson's can have a big impact on all aspects of daily living as the condition progresses. Many people with Parkinson's become increasingly reliant on care and support in order to maintain their quality of life. Ultimately care needs are such that a person is likely to need a comprehensive package of care at home, or in long term residential care. However people with Parkinson's face a number of barriers to good quality long term care:

Funding

As care arranged by social services is means tested, the outcome of any decision can have significant financial consequences for the person with Parkinson's and their family.¹ If a person is just over the means testing limit, they may face a lifetime of paying for care and may have to sell their home to enter residential care. This can seem extremely unfair. The rapid increases in charges for social care, and differences in charging policies also adds to the complexity and variation in the system.

Information and choice

Information about services and support is often not easily available, and for those organising and paying for their own care it is particularly difficult to get advice and information. Despite encouragement for people to exercise choice, including equipping them with their own budgets, there may be little real choice of services in a locality, especially for younger people with Parkinson's. Where people are given their own budgets or payments, these may not be of a level to ensure they can buy a service of their choice.

Rationing

There is a perception that the current system is driven by local authority budgets and services available rather than meeting the needs of users. This is most commonly expressed in the social care eligibility criteria in operation, with a number of authorities providing services only for those with "critical" or "substantial" care needs. This has led to people with Parkinson's being unable to get the support they need or who have been told that support was being withdrawn for no reason.

Joining up health and social care

There is a lack of joined up working between health and social care, with people repeating their needs to many different people. The lack of integration means health and social care budgets can become a battleground, with the person at the centre confused as to where the boundary between health and social care lies. This is most apparent with NHS

¹ Note that free personal and nursing care in Scotland for those over 65 may mean less of a financial impact on those who are eligible for social care, as the state is contributing towards people's care costs in nursing homes, care homes and in their own homes.

continuing care.² People say that their long term care needs are ignored – preventative measures and early interventions are given a low priority in most areas. Simple things like aids and adaptations that can provide cost-effective "low level" support are subject to long waits.

Quality

Despite regulation and assessment of services, there remain concerns over the quality of care services locally and whether information on services can be trusted. There are concerns that the way services are commissioned can be rigid and inflexible, leaving people feeling rushed and neglected. Issues around protection of vulnerable adults remain a concern. The shortfall in funding exacerbates low pay in the workforce, which suffers from high turnover and this damages continuity of care. People with Parkinson's say that many staff working in care settings have insufficient understanding of the condition.

What's the evidence?

Findings from survey and inquiry

There is clear evidence of unmet need amongst people with Parkinson's. A survey of Parkinson's UK members³ found, for example, that of the 26% of people with Parkinson's who needed personal care services, such as help with dressing or bathing, one in five (19%) were not receiving this support. One in ten respondents said that their home was unsuitable to live in, because it needed adaptations or because of steps or stairs. Of those who purchased the equipment they needed to live at home, many did so without professional advice, for example 49% of those purchasing bathroom aids and 43% of those installing ramps or rails outside their house.

There is a need for better information. People with Parkinson's and their carers do not know about the support available and their right to assessment. For example, our recent membership survey identified that only 11% of carers were actually receiving support from social services, a fall from 16% in the 1997 survey. Seven out of ten carers were not aware of their right to a carer's assessment.

These findings were reiterated in a parliamentary inquiry⁴ on services for people with Parkinson's.

² Please see our policy position statement NHS continuing care (2010)

³ Parkinson's UK. *Life with Parkinson's today – room for improvement*. (2008)

⁴ All Party Parliamentary Group for Parkinson's Disease. *Please mind the gap – Parkinson's disease services today* (2009).

About Parkinson's UK

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Response submitted by Carol Smith, Campaigns, Influence and Service Development Officer for Wales

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15 December 2011

Appendix

The following was submitted by a relative:

In response to your request for feedback you are welcome to make any use you wish of info below and I am happy to give oral evidence if required.

Re paragraph 1: 'accessibility of alternative community-based services'

Though extremely and unfairly expensive I found this support very easy to access, generally of good quality and very effective. (I set up my own care plan to keep my Mum in her home as was her wish, building up from an hour's support a day to 24/7 using a number of private domiciliary care agencies over

a period of 5 years.) Mum's assessed entitlement to care by Social Services was far from adequate for a number of reasons. Although the personnel did their best, the system they are locked into does not, from my observations, work in the best interests of those they serve. This is basically because the system is understaffed and under resourced (resulting unreliable punctuality, inappropriate visiting times which are far too short anyway, many carers overstressed, many not properly trained, low morale, lack of continuity because of frequent staff changes, lack of communication, not enough flexibility to meet individual needs.....).

With regards to access to community based OTs and Physio advice - I always had a prompt and excellent response to requests for assessment/advice to carers as Mum's health/mobility declined. I also had an excellent response from the District Nurse team but there were times when they were understaffed meaning that insufficient visits could be made to monitor and treat Mum's pressure sore. Services providing items such as handrails, slip sheets, pressure cushions, bath lifts, hoists etc - all excellent with the exception of the acquisition of a hospital bed and a ripple mattress (apparently these are 'post code lottery' items). Gwent Care and Repair Service - fantastic.

Re paragraph 3: 'the experience of service users and their families'

Mum presently receiving excellent care in a residential/nursing home though from what I understand (talking to many carers/friends with parents in homes) most homes, though 'task efficient' regarding physical care, lack in the provision of supporting individual 'emotional well being' - life is too institutionalised. While making residential care more like 'home' is an undoubted challenge I doubt there is much transfer of expertise from 'beacon' homes or enough finance to access advice from Specialist Nurses (e/g Parkinson's Nurses). Catering for a diversity of needs requires additional staff, physical care is just not enough. *There's something huge missing between living at home and being in a home ...* there's got to be a way we can improve this (greater interaction with local community especially local schools, better accommodation to allow quality whole family visits in a private comfy room, additional staff to allow time to encourage greater independence and purposeful activities.... improved indoor environment and greater access to garden areas). My greatest heart ache is the tremendous change in Mum's emotional/well being between what a home provides and what was provided for her at home.

Parkinson's UK Cymru

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Date: 30 March 2012
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Mr Darren Millar AM
Chair of the Public Accounts Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF99 1NA

Dear Chair

CARE AND SOCIAL SERVICES INSPECTORATE WALES

As you may recall, my programme of value for money studies previously included a commitment to undertake a review of the Care and Social Services Inspectorate Wales (CSSIW). However, as I indicated in my recent briefing paper, which the Committee considered on 31 January 2012, I have now decided not to proceed with a detailed review of CSSIW. This letter explains my reasons for that decision and also summarises findings from work on CSSIW undertaken by my staff during 2011.

Concerns about the effectiveness of CSSIW's regulatory regime, specifically in respect of adult care homes (including those providing nursing care), were raised by a BBC Wales Week In Week Out programme broadcast on 25 November 2009. The BBC investigation which underpinned that programme centred on evidence collected in relation to Glyndwr Care Home in Ystrad, Rhondda Cynon Taf. Jonathan Morgan, as the then Chair of the Committee, wrote to Jeremy Colman, as the then Auditor General, requesting that the Wales Audit Office carry out an investigation of the performance of CSSIW in light of the issues raised by the BBC programme. You also wrote to Mr Colman about this matter in December 2009, in your role as Chair of the then Health, Wellbeing and Local Government Committee.

Following the Week In Week Out programme, CSSIW initiated a fundamental review and overhaul of its regulatory activities. As well as following-up the specific issues and concerns raised in relation to Glyndwr Care Home, CSSIW has since embarked on a 'Review of Regulation', leading into the development in 2011 of a wider ranging 'Modernisation Programme', which will affect the full breadth of CSSIW's regulatory activity and the way the organisation is structured. The case for change also stems from the need for CSSIW to ensure that it is able to deliver its regulatory functions effectively while, at the same time, responding to the financial pressures facing all

public services. CSSIW is also taking action to comply with EU regulations and meet user expectations by improving its provision of on-line services and, more generally, it has needed to respond to the issues identified in the Welsh Government's February 2011 paper, *Sustainable Social Services for Wales: A Framework for Action* and the new *Social Services (Wales) Bill*.

Given the level of review and change now underway within CSSIW, I decided that it would not be helpful or productive to seek to carry out an audit of CSSIW in parallel. In arriving at this decision I also took into account the scope of the Health and Social Care Committee's current inquiry into residential care for older people, which includes consideration of the effectiveness of the current regulatory regime. I understand that CSSIW has submitted a paper to that Committee and will be giving further evidence in May 2011.

Annexed to this letter is our assessment of the action taken by CSSIW over the past two years to address some of the immediate issues of concern that emerged in late 2009, and of work taken forward as part of the Review of Regulation project and now the ongoing Modernisation Programme. Our findings and conclusions are based on a review of a range of documents supplied by CSSIW about the delivery of its regulatory functions, including the specific circumstances of its regulation of Glyndwr Care Home, and the action CSSIW has taken to improve its processes. My staff have discussed relevant matters in meetings with CSSIW senior managers, regional directors and regional regulation managers. They have also met other CSSIW staff responsible for the Modernisation Programme and for governance and information technology, as well as meeting staff from the Welsh Government's legal services team.

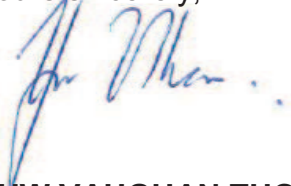
The scale of CSSIW's change programme has been significant and the direction of travel is positive. The overall pace of change has been constrained by capacity issues, including the need to balance progressing organisational change against the demands of day to day business. Nevertheless, CSSIW has improved its performance in the delivery of its planned inspection regime. It expects to complete 100 per cent of planned inspections in 2011-12, and is confident that the action it has taken to improve its regulatory processes since late 2009 has resulted in work being delivered to a better professional standard. CSSIW has made good progress with its Modernisation Programme during 2011-12 and now plans to introduce new regulatory processes, supported by a new organisational structure, from the start of 2012-13.

I retain a keen interest in the progress that CSSIW is making in implementing its change programme and the impact that has on the effectiveness of its regulatory functions. The Wales Audit Office is already represented on CSSIW's national stakeholder board for the Modernisation Programme and I will report to the Committee should any issues of significance emerge. In the meantime, I trust that you find this information helpful as a report on the progress that CSSIW is making in the light of the issues of concern the Committee raised previously.

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I am copying this letter to the Chair of the Health and Social Care Committee to inform its current inquiry, and in light of the concerns you raised when Chair of its predecessor Committee.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Huw Vaughan Thomas', is written over a faint, light blue circular watermark or stamp.

HUW VAUGHAN THOMAS
AUDITOR GENERAL FOR WALES

Enc

cc Mr Mark Drakeford AM, Chair, Health and Social Care Committee

Annex: Summary of key action taken by CSSIW that should address weaknesses in its regulation of care homes

CSSIW's regulatory activities aim to ensure that good quality care is provided in care homes

1. The Care and Social Services Inspectorate Wales (CSSIW) was created in April 2007, following the merger of the former Social Services Inspectorate Wales and the former Care Standards Inspectorate Wales. CSSIW is responsible for inspecting and reviewing local authority social services and regulating and inspecting social care and early years settings and agencies. CSSIW carries out its functions on behalf of Welsh Ministers. While professionally independent, CSSIW is part of the Welsh Government's Local Government and Communities Directorate.
2. CSSIW's regulatory functions in respect of care homes for adults, and other care settings, include:
 - *Registration*: deciding who can provide these services;
 - *Inspection*: inspecting registered services against the regulations in the Care Standards Act 2000, and reporting the results of these inspections;
 - *Complaints*: investigating and dealing with complaints – if they cannot be dealt with by providers;
 - *Compliance*: ensuring compliance with relevant regulations; and
 - *Enforcement*: taking enforcement action to ensure the requirements of the Care Standards Act 2000 and associated regulations are met.
3. At 31 December 2011, CSSIW was responsible for regulating 6,240 service settings, of which around one in nine was a care home for adults aged 65 and over¹.
4. CSSIW's regulatory activities aim to ensure that care home providers provide good quality care and comply with statutory requirements. However, *Sustainable Social Services for Wales: A Framework for Action*² emphasises that: "the prime responsibility for ensuring quality, a clear voice and control by service users, safeguarding and protection lies with organisations themselves, with professionals and with commissioners of services - and not with regulators and inspectors".
5. There is a regulatory requirement for the registered providers of care homes to undertake their own quality monitoring. Commissioning organisations

¹ Service settings and places regulated by CSSIW, 31 December 2011, CSSIW, February 2012.

² *Sustainable Social Services for Wales: A Framework for Action*, Welsh Government, February 2011.

(local authorities and health boards) should also be undertaking their own work to monitor the quality of service provision. The Welsh Government's Director General for Health and Social Services and Children has recently requested information from Health Boards about their arrangements for monitoring the quality of care in care home settings and has asked that they engage their internal auditors in reviewing those arrangements. CSSIW also plans to carry out a national review of local government commissioning arrangements.

CSSIW's 2009 review of the way it had discharged its functions in relation to Glyndwr Care Home highlighted some clear weaknesses that were unlikely to be unique to this care setting

6. On 25 November 2009, the BBC's Week In Week Out programme focused on whether vulnerable elderly people's rights were being properly protected by CSSIW. The BBC investigation which underpinned the programme centred on evidence collected in relation to Glyndwr Care Home in Ystrad, Rhondda Cynon Taf. The concerns raised with us as a result of the Week In Week Out programme related to:
- the extent to which CSSIW's regulation of care homes provides adequate assurance that they are being run by staff who are properly vetted, resourced, trained and managed;
 - whether CSSIW's monitoring and inspection procedures were sufficiently robust to ensure that care homes comply with their statutory obligations;
 - whether the sanctions available to CSSIW were being used effectively; and
 - whether CSSIW's information management processes were sufficiently robust to fully assess performance, including the extent of poor performance, non-compliance and repeat offending.
7. In response to the issues raised by the Week In Week Out programme, CSSIW undertook an immediate review of its previous regulation of Glyndwr Care Home. The review found that issues of concern at the home had been identified over a number of years, particularly in relation to medicines management. On various occasions, including following two Protection of Vulnerable Adult (POVA) referrals³ in April and August 2009 and the annual inspection in May 2009, CSSIW identified that it had missed potential opportunities to take firmer regulatory action. The review identified a range of shortcomings in CSSIW, including:

³ A POVA referral is the direct reporting of an allegation, concern or disclosure – relating to possible abuse – to a statutory organisation (local authority social services, police, or NHS body).

- Work pressures created by staff shortages. The regional regulation team for Mid and South Wales had also been dealing with numerous enforcement concerns relating to other care settings, which, it appears, had taken priority.
- A reticence among staff to take enforcement action because they perceived that such action may not have been supported by the Welsh Government's legal services, and because of the resource implications associated with taking enforcement action.
- A tension between CSSIW's distinct regulatory role and the role of other agencies, notably in this case the role of the police in POVA investigations.
- Inappropriate referral of complaints and POVA referrals for local resolution. Individual care home settings are required to demonstrate that they have put in place a clear, effective and fair complaints procedure which promotes local resolution wherever possible. However, CSSIW's review concluded that, given their nature and in light of growing concerns about the performance of the registered manager, some complaints and POVA referrals in relation to Glyndwr Care Home had been inappropriately referred for local resolution.
- Concerns about the way in which regulatory requirements⁴ had been identified and dealt with following the inspection visit in May 2009 (reported in August 2009). These concerns related to: a lack of focus on requirements outstanding from previous inspections; opportunities for the inspection report to have been clearer and more focused in identifying specific regulatory breaches: and the issue of compliance notifications at the time of reporting rather than at the time of inspection.
- Weaknesses in underpinning quality assurance and management information systems. Staff indicated that it was not easy to access information on individual care settings. The review also pointed to an apparent lack of any comprehensive case analysis or documented chronology of events specifically in relation to Glyndwr Care Home, and to the general absence of a structured risk management process and alert system and of systems to monitor activity. Staff turnover and/or absence within the team responsible for the regulation of Glyndwr Care Home exacerbated these shortcomings in information management.

8. The review concluded that lessons needed to be learned at all levels within CSSIW and that it was unlikely that the issues raised were entirely unique to

⁴ CSSIW's inspection reports set out any formal requirements for the care setting in terms of ensuring compliance with specific regulations. The reports also identify the timescales for notifying CSSIW of action taken to achieve compliance. In addition to these formal requirements, inspection reports may identify other action needing to be taken to improve care in line with good practice.

this one care setting, or solely to the management of activity in the Mid and South Wales region.

The most recent inspection of Glyndwr Care Home, reported in June 2011, concluded that all requirements outstanding from previous inspections had been appropriately complied with, but it also highlighted areas for further improvement, particularly in relation to care planning and staffing

9. Following the Week In Week Out programme on 25 November 2009, CSSIW undertook an unannounced visit to Glyndwr Care Home on 27 November 2009, with further unannounced visits in December 2009, March 2010 and May 2010. CSSIW's next formal inspection drew on the findings from three further unannounced visits in July and August 2010. In addition to the normal inspection processes, the visits in July and August 2010 incorporated a particular focus on infection control arrangements. This work informed CSSIW's thematic review of infection control standards in all care homes for adults.
10. CSSIW published its inspection report in October 2010. The report pointed to improvements since the previous inspection (reported in August 2009) in respect of: recruitment practices and related documentation; compliance with requirements to confirm in writing to service users, following initial assessment, that the home can meet their needs; the production of an annual quality assurance report (although a requirement for quarterly monitoring visits by the registered provider was still outstanding); and improved provision of daytime activities for residents. However, the report found that the overall services and standard of care could be improved by the provision of more staff. It also pointed to the need for improved record keeping and remedial work in respect of the nurse call system and electrical installation. Infection control arrangements were also deemed to be unsatisfactory.
11. The inspection report contained 12 specific requirements, five of which related to CSSIW's findings on infection control. Of the other seven requirements, four were outstanding from previous inspections. A requirement in relation to ensuring consistency between service users' care plans developed by staff at the home and related documentation produced by commissioning services had originally been identified by CSSIW for completion by mid-April 2007.
12. The most recent inspection report for Glyndwr Care Home, dated June 2011, was based on an unannounced inspection visit in April 2011. The report pointed to ongoing concerns about staff recruitment and retention, particularly in respect of registered nurses. These concerns had been identified by CSSIW and local commissioning bodies as part of 'escalating concerns' procedures initiated since the 2010 inspection. As a result, both the local authority social services department and the Local Health Board had imposed a formal embargo on admissions. CSSIW had also had regular contact with the home since the previous inspection report in October 2010. The June 2011 report noted that improvements had been made and that the embargo had been lifted, although it emphasised that these improvements needed to be sustained to provide stability and continuity of care for service users.

13. The June 2011 report highlighted various areas for further improvement, particularly in relation to care planning and staffing. However, the issues raised did not necessitate any specific and new regulatory requirements requiring notification of compliance by the registered provider. The report indicates that the requirements outstanding from previous inspections had been appropriately complied with.
14. Since CSSIW's most recent inspection, reported in June 2011, the registered provider has changed the name of the care home to Mill View Care Home.

CSSIW has addressed some of the immediate concerns it identified in 2009 about the way it had discharged its functions in relation to Glyndwr Care Home, but a fuller response to these issues has been subsumed within a Review of Regulation project in 2010 and, since early 2011, a wider-ranging Modernisation Programme

15. The areas for action identified by CSSIW in late 2009 related to performance management and related systems; staff numbers and staff training and development; information system improvements; working with others; and broader policy implications. Several of the identified actions have since been subsumed within the scope of CSSIW's Review of Regulation project in 2010 and, since early 2011, the wider-ranging Modernisation Programme. However, more immediate action taken outside of the scope of that work has included the following:
 - At a national, regional and individual setting level, CSSIW has strengthened its arrangements in terms of monitoring and reporting progress with, and addressing any issues of concern relating to, the delivery of its regulatory functions. However, there are still recognised limitations in its information systems, and CSSIW's key performance measures are output, rather than outcome, focused. The development of performance measures that are focused on outcomes features as part of CSSIW's Modernisation Programme.
 - In strengthening line management arrangements, CSSIW has introduced more robust quality assurance processes to oversee the reporting of inspection findings and the requirements placed on providers as a result.
 - CSSIW has provided additional guidance and training for staff, notably regarding the handling of complaints and adult protection issues. This follows guidance issued in November 2009 on CSSIW's role in relation to other statutory bodies as regards adult protection policy and procedures. New Interim All Wales Adult Protection Policy and Procedures, relevant to all agencies involved in this work, were also developed in 2010 following work commissioned by the four adult

protection fora in Wales⁵. The development of these policies and procedures is but one part of a wider body of recent work on adult protection arrangements in Wales. This work has included CSSIW's own national inspection of adult protection arrangements⁶, and a report by the Welsh Government's Protection of Vulnerable Adults Project Board⁷. Building on this work, the Welsh Government's *Social Services (Wales) Bill* will include a statutory framework for adult and child protection.

- CSSIW deployed additional staff to strengthen management arrangements in the Mid and South Wales region and to address staff shortages. However, a residual concern about capacity and workloads remained in all regions, exacerbated by the impact of the Welsh Government's location strategy and voluntary severance initiatives. In addition, work undertaken by CSSIW in 2010 highlighted a lack of consistency in the way inspectors were spending their time. CSSIW had also identified more general concerns about the amount of staff time being spent on the management of complaints, notwithstanding that there will be times when local resolution is not appropriate, and in the management of registration. CSSIW's plans for organisational restructuring and the introduction of leaner processes as part of the Modernisation Programme are providing the basis for more sustainable workload management.
- CSSIW reviewed all outstanding requirements placed upon providers following inspection visits. This work highlighted issues in relation to outstanding requirements that needed following up. However, CSSIW found that providers had, in some cases, responded to these requirements, but its information systems had not been updated accordingly.
- CSSIW has developed revised guidance for staff on the use of chronologies of events and the regional managers emphasised that staff were now better aware of their importance, particularly in supporting any possible action by legal services. While they recognised the limitations of the information system used to hold regulatory data, some of the CSSIW regional managers we met emphasised that, if used properly, the system is capable of providing an overview of regulatory activity over time.
- During 2010-11, CSSIW also developed new processes for 'services of concern' reviews, which provide a more rigorous approach to reviewing

⁵ The four multi-agency fora are responsible for developing, agreeing and implementing policies and procedures for the protection of vulnerable adults. The four fora are aligned geographically with the four police authorities in Wales (South Wales, Gwent, Dyfed Powys and North Wales).

⁶ *National Inspection of Adult Protection – All Wales Overview*, CSSIW, March 2010.

⁷ *Report of the Protection of Vulnerable Adults Project Board*, Protection of Vulnerable Adults Project Board, February 2011.

available information about a particular setting and further action in terms of compliance and potential enforcement activity. CSSIW will instigate these reviews if, following an inspection and any subsequent meetings with CSSIW, the care provider still fails to demonstrate compliance with regulatory requirements.

Following concerns about the prospects for successful delivery, CSSIW strengthened its Modernisation Programme control arrangements and changed the Programme's priorities

The main purpose of the Review of Regulation project in 2010 was to develop the case for new business processes and investment in new information systems, rather than to implement change

16. The concerns identified in 2009 had highlighted that CSSIW's existing business processes and information systems were not fully fit for purpose. The main purpose of CSSIW's Review of Regulation project in 2010 was to support decisions on the viability of implementing new business processes and associated information systems. The work planned in 2010 was, in essence, a scoping project to support the case for change, as opposed to being the vehicle for implementing change. The project was managed by CSSIW staff but supported by external consultants (at a cost of £311,000, plus VAT).
17. The Review of Regulation project took longer to complete than had been expected. At the start of the project in February 2010, it was envisaged that the outline business case would be prepared by the end of July 2010. This timeline was then extended so that the proposed ICT solution for CSSIW could be properly evidenced and to ascertain whether a suitable ICT solution might already have been procured by the Welsh Government for use elsewhere within the organisation.
18. When the Review of Regulation Project Board considered the outline business case in December 2010, it recognised that more work was needed to clarify expected benefits. The indicative costs of delivering CSSIW's preferred ICT solution, including the value of staff time, were estimated at £8.3 million (excluding VAT). This figure included certain elements of work that are now expected to be absorbed as part of a separate Welsh-Government-wide project to support the development of secure on-line services (the Enabling On-line Services project). In CSSIW's case, such on-line services would include registration for care providers.
19. The Review of Regulation recommended the full establishment of a CSSIW change programme – the Modernisation Programme launched in January 2011 – to be supported by recruitment to new programme and project management roles⁸. The Review of Regulation also recommended that, once established, the Modernisation Programme's management arrangements

⁸ The CSSIW Project Director and Project Manager for the Review of Regulation have since left the organisation.

should be reviewed by the Welsh Government's Gateway Review Team. Other recommendations relating to staff communication and further work on benefits profiling and process mapping, have been taken forward within the scope of the Modernisation Programme, which is framed around three core workstreams:

- process development (spanning the full range of CSSIW's regulatory functions);
- organisational development (management structures, workforce planning and learning and development); and
- information and communications technology (ICT) development.

20. CSSIW developed the Strategic Outline Case for the Modernisation Programme between January and April 2011. That document identified plans for full implementation of new regulatory processes by the start of 2012-13, with organisational development work ongoing through to mid 2012-13 and ICT development to be completed by the end of 2012-13.

A Gateway Review in May 2011 identified significant concerns about CSSIW's prospects for delivering the Modernisation Programme within intended timescales and questioned the focus, at that time, on ICT development

21. In May 2011, Welsh Government officials completed a Gateway Review⁹ of CSSIW's plans for the Modernisation Programme. The Gateway Review identified significant concerns about CSSIW's prospects for delivering the Programme within its intended timescales. The review team gave the Programme a 'red' rating in terms of delivery confidence. This rating reflected an assessment that: *"Successful delivery of the Programme appears to be unachievable. There are major issues on programme definition, schedule, budget required, and quality or benefits delivery, which at this stage do not appear to be manageable or resolvable. The Programme may need baselining and/or its overall viability re-assessed"*. The Gateway Review recognised that significant development work was underway but that it was taking place largely outside of any formal programme control, for example in terms of arrangements for agreeing priorities, reporting progress and managing interdependencies.
22. The Gateway Review observed that, as with the focus of the Review of Regulation, the early focus of the Modernisation Programme had been about defining the full business case to fund ICT development. Yet few of the people within CSSIW spoken to by the Gateway Review team had identified ICT development as the top priority. The Gateway Review raised concerns

⁹ The Gateway Review process was developed by the Office for Government Commerce (which now operates through the Government Procurement Service, an executive agency of the UK Government's Cabinet Office). The purpose of the process is to examine programmes and projects at key points in their lifecycle and to provide assurance in terms of progress to the next stage of development. The Gateway Review of CSSIW's modernisation programme was undertaken by Welsh Government officials external to CSSIW.

that the source material used to define the ICT requirements was already out of date, as it had not been updated to reflect process developments. It questioned whether the Welsh Government's Enabling Government¹⁰ team would willingly accept a CSSIW bid for resources to support the development and procurement of a new system. The Gateway Review also expressed concern about the inter-dependency between CSSIW's aspirations and timescales for the Welsh-Government-wide Enabling On-line Services project.

CSSIW strengthened its Modernisation Programme control arrangements and changed the Programme's priorities, resulting in a positive follow-up Gateway Review in September 2011

23. In response to the Gateway Review, CSSIW revisited the Modernisation Programme's priorities and decided to focus on the development and implementation of planned process and structural changes, and related organisational development work, on the basis that the ICT requirement could not be fully understood and defined in isolation. The appointment of a project manager for the ICT development workstream was deferred until Spring 2012. In the meantime, CSSIW has been working within the constraints of its current ICT system to meet business needs in the short-term. CSSIW managers recognised that, regardless of what system is used, the challenge will be to ensure that field-staff and managers are better able to understand and use it than is the case with the present system.
24. The Gateway Review team undertook a follow-up review in September 2011 to consider the action that CSSIW had taken in response to the recommendations of its May 2011 review. In light of the Programme being refocused and the action taken to formalise programme management and programme board arrangements, the reviewers significantly upgraded their delivery confidence assessment to a 'green' rating.

The general direction of travel has been positive and CSSIW now plans to introduce new regulatory processes, supported by a new organisational structure, from the start of 2012-13

25. The May 2011 Gateway Review commented on the perception of some field staff that the Modernisation Programme had stalled. Some of the regional managers we spoke to also noted that the Review of Regulation had perhaps promised too much too soon and that this had affected staff morale. However, during 2011 CSSIW staff and the representatives from the Welsh Government's legal services were actively engaged in events designed to support the development of proposals for new and leaner regulatory processes. Bringing staff together to help develop new processes again highlighted variations in local practice and understanding. All-staff training on the new regulatory processes arising from this work is currently underway.

¹⁰ The Welsh Government's 'Enabling Government' portfolio was set up in 2007-08 (as the Business Development Portfolio). Its purpose is to develop and take forward a portfolio of significant change programmes and projects, including ICT business change.

26. As the May 2011 Gateway Review identified, the case for change is well founded and the direction of travel appears to have been generally accepted within the organisation and by external stakeholders. Some of the key proposals in terms of organisational structure and process redesign include:
- With effect from 1 April 2012, CSSIW will be formally restructured from four regional management teams to three, although a three region approach has, in practice, been operating since October 2011. The number of Assistant Chief Inspector posts also reduces from four to three (covering operations, strategy, and enabling functions). The new structure will be 'de-layered', reducing to no more than three the number of management layers between the Chief Inspector and those employed at 'team-band' level. This de-layering is consistent with wider changes across the Welsh Government. Job descriptions and gradings have been reviewed, with a formal five-week consultation currently underway. CSSIW expects to complete the matching and selection of staff to posts by June 2012, with a view to full implementation by October 2012.
 - As part of the restructuring, each region will have a dedicated registration and enforcement team. This change is intended to improve the efficiency and consistency of these processes, and to ensure that there is a dedicated resource available to deliver these functions, separate from those staff responsible for inspections. The intention is that CSSIW registration and enforcement teams will work closely with the Care Council for Wales in co-ordinating enforcement activity to ensure that registered or licensed managers are held to account for shortfalls in performance. CSSIW has also been discussing with the Care Council for Wales opportunities to work together to simplify registration or licensing arrangements¹¹. Processes for assessing and completing application forms are being simplified, although full on-line services are no longer an ambition in the short-term. CSSIW is awaiting the outcomes from consultation on the Social Services (Wales) Bill before finalising its remodelling of registration processes.
 - Also under the restructuring proposals, responsibilities for the management and delivery of inspection work in relation to individual care settings and local authority social services will be integrated, addressing a separation that has existed since the creation of CSSIW in 2007.
 - CSSIW has been exploring options for the use of lay inspectors to support delivery of its care home inspections, and workforce planning has also identified the need to recruit and develop trainee inspectors.

¹¹ In its submission to the Health and Social Care Committee, CSSIW said that it has been developing a broader programme of collaborative working with the Care Council for Wales in response to the Welsh Government's February 2011 paper, *Sustainable Social Services for Wales: A Framework for Action*. The programme will include pooling knowledge and information to enable a better understanding of the staffing resources available in residential care for older adults.

- While there are challenges to CSSIW to reduce any unnecessary regulatory burden on service providers, there also appears to be little appetite for a reduction in the requirement for annual inspections of care homes. However, CSSIW intends to shift the focus of inspection more clearly towards the quality of experience for people using services. CSSIW intends to reshape its care home inspection processes and reporting to focus on the following four core themes in respect of regulated care settings:
 - *Quality of life:* This includes service users' rights and control (in terms of choice and influence over their care), fulfilment, physical wellbeing and emotional wellbeing.
 - *Quality of staffing:* This theme focuses on professional competence and confidence, sufficiency, support and supervision in regulated settings. Of relevance to this theme, *the Care Homes (Wales) (Miscellaneous Amendments) Regulations 2011* came into force on 1 June 2011. These new regulations now require that all managers of care homes for adults in Wales, including those homes registered to provide nursing care, must be registered as a manager with the Care Council for Wales.
 - *Quality of leadership and management:* This theme covers clarity of vision and purpose, quality assurance, diligence and compliance, improvement and sustainability. CSSIW has remodelled the annual self assessments returned by registered providers to evidence corporate responsibility and their commitment to improvement.
 - *Quality of the environment:* This theme covers ambience, accessibility, facilities and safety.

CSSIW has worked with the University of Bradford to develop a 'Short Observational Framework for Inspection' method based on these inspection themes. Training for inspectors has started, with a view to full roll-out from June 2012, Plans for the development of clear evaluative judgements against each of these themes are under discussion. CSSIW is keen to align these plans with the national outcomes framework for social care proposed in *Sustainable Social Services for Wales: A Framework for Action*.

- To support a more risk-based and focused approach to inspection, CSSIW has developed a new electronic risk assessment tool framed, initially at least, around the themes set out in national minimum standards for care homes for older people¹². Implemented in October 2011, to date the tool has been applied to all settings with the exception of children's day care where its use was not considered appropriate. Risk assessment will be undertaken at the point of registration and annually thereafter. The tool will also be used when specific concerns come to light and CSSIW expects that, in the medium to long-term, it will support a better targeted and more efficient inspection regime.
- From April 2012, CSSIW's inspection methodology will also differentiate between baseline inspections, covering a fuller range of issues, and focused inspections targeting particular issues of concern.
- CSSIW is also developing a tool to measure the quality of service from a service user perspective, to be used in conjunction with the risk assessment tool. CSSIW plans to consult stakeholders on its proposals for the quality measurement tool, early in 2012-13.
- Building on work that pre-dated the formal establishment of the Modernisation Programme in January 2011, CSSIW has implemented revised processes for self-assessment by, and data collection from, providers in respect of individual care settings. The new arrangements were discussed with providers at a workshop in February 2011 and introduced as the foundation for all inspections of care settings in 2011-12. They include:
 - an annual collection of data about service users, staff and the general characteristics of the setting; and
 - a self-assessment of service form exploring how providers review and record the quality of their services, how they involve service users and other stakeholders in that work, and plans for future service development.

During 2011-12, CSSIW has been reviewing the effectiveness of these revised data collection and self assessment processes with a view to introducing further changes for 2012-13, and to ensure alignment with the proposed changes to inspection processes and the work undertaken to develop the risk assessment tool. The timing of the data collection and self assessment processes is currently connected with CSSIW's inspection timetable for individual settings. CSSIW has indicated that it intends to move to on-line data collection, with

¹² *National Minimum Standards for Care Homes for Older People*, Welsh Government, March 2004. CSSIW uses these standards to help determine whether care homes are providing adequate care, meeting the needs of service users and are otherwise operating in accordance with regulatory requirements.

providers submitting information for all settings during a fixed time period. These changes are intended to help CSSIW prioritise its annual inspection work on the basis of the information collected and to support the aggregation and publication of summary information.

- New enforcement processes have been developed, for full implementation from April 2012, and processes for assessing and completing registration forms are being simplified, although full on-line services are no longer an ambition in the short-term. CSSIW is awaiting the outcomes from consultation on the Social Services (Wales) Bill before finalising its remodelling of registration processes.
- Alongside the development of new registration, inspection and enforcement processes, CSSIW has also been consulting on a new engagement strategy, to support its intention of putting users and carers at the heart of what it does. CSSIW plans to establish a national and three regional stakeholder boards to engage with service users, providers, commissioners and other third sector organisations. CSSIW intends that members of these groups will support the lay inspection function and participate in quality assurance of CSSIW's inspection reports.
- CSSIW has also been trialling new processes for handling complaints and for adult protection that are consistent with proposals set out in the consultation on the Social Services (Wales) Bill. These new processes will be implemented in full from 1 April 2012.

The challenge, in terms of CSSIW's capacity to develop and implement new processes and structures while, at the same time, managing its day to day business, remains

27. Even if CSSIW had been able to commit more resources to speed up the development and delivery of the Review of Regulation and the Modernisation Programme, senior managers have raised concerns about the business-continuity risks of trying to deliver change too quickly. Well-publicised concerns about financial resilience in the care home sector, specifically in respect of Southern Cross, and CSSIW's own response to the issues raised by the BBC Panorama programme on the Winterbourne View Care Home in Bristol in May 2011, have also diverted attention and resources away from planned work. However, these events have, as in the case of CSSIW's response to the Week In Week Out programme in November 2009, also informed the plans for change. For example:

- CSSIW is intending to build in financial expertise within its registration and enforcement teams to ensure providers have sustainable and responsibly structured businesses; and
- CSSIW responded to the events highlighted by the Panorama programme by undertaking, in July 2011, focused inspections of 13 care homes owned by the same company in North Wales. That work provided an opportunity to test out new inspection methodologies,

drawing together a team of inspectors from across Wales, and highlighted the benefits of undertaking coordinated inspection work focusing on individual providers rather than individual settings, for example in highlighting common areas of weakness. One key finding from the inspections was that the service provider was not carrying out its own quality monitoring visits in an effective way.

28. CSSIW has also had to deal with the loss of staff because of the Welsh Government's wider location strategy and voluntary severance initiatives, as well as its response to the planned reduction in its budget. While these developments reinforce the case for change, they have presented particular challenges in terms of maintaining day to day operations.
- In cash terms, CSSIW's annual budget is expected to reduce steadily from £16.5 million in 2010-11 to just under £14.5 million in 2013-14 (a 12.5 per cent reduction in cash terms, but a 19 per cent reduction in real terms).
 - Figures supplied to us by CSSIW in mid-2011 indicate that, commensurate with these budget reductions, staff numbers need to reduce from 309 posts in 2010-11 to around 270 posts in 2013-14. These projections were dependent on final decisions on organisational restructuring and the pace of change in terms of streamlining regulatory processes and introducing new information systems.
 - While the Welsh Government's voluntary severance and location strategy plans potentially support the direction of travel in terms of staff numbers, their impact has been largely outside of CSSIW's direct control. Twenty CSSIW staff left the organisation under voluntary severance in Autumn 2010, and a further 31 staff left in summer 2011. CSSIW told us that it would have preferred not to have lost some of the staff who have left the organisation.
 - In accordance with the Welsh Government's location strategy, CSSIW has reduced its number of offices from 13 to just three. The process of office closures was completed in December 2011. Some staff have chosen to pursue opportunities in other parts of the Welsh Government rather than relocating with CSSIW. Regional managers have noted a particular impact in terms of the loss of experienced business support staff. While CSSIW has been recruiting back into some posts, CSSIW managers have expressed frustration at the slow pace of the Welsh Government's recruitment processes.
29. Given these workforce challenges, the caseloads for individual inspectors have inevitably increased. However, the changes CSSIW has been introducing to its regulatory processes are designed to help deliver this work more efficiently and effectively, and manage workloads responsibly. CSSIW is, therefore, confident that it is delivering its work to a better professional standard than was previously the case.

30. CSSIW reported that in 2010-11 it had completed 98 per cent of planned inspections across all settings, up from 92 per cent in 2008-09 and 97 per cent in 2009-10¹³. The main shortfall in 2010-11 was in the Mid and South Wales region which achieved 93 per cent completion. Reported figures for care homes for adults aged over 65 show 100 per cent completion. For 2011-12, CSSIW expects to be able to report 100 per cent completion of its planned inspection programme, with most inspectors having completed their inspection caseload by the end of February 2012.
31. In 2010-11, 91 per cent of inspection reports were made public within 63 days (only 80 per cent in the Mid and South Wales region), against a target of 100 per cent. In 2009-10 90 per cent of inspection reports were made public within 63 days. Only 30 per cent of investigations into complaints were completed and reported on within 42 days, down from 48 per cent in 2009-10 and against a target of 100 per cent. Figures for investigations into complaints at older adult care homes that were completed and reported on within 42 days fell from 53 per cent in 2009-10 to 38 per cent in 2010-11. Despite reporting these key performance indicators for complaints, CSSIW told us that many of the complaints it receives do not relate directly to concerns about standards of care and that it does not, therefore, have any real locus to investigate such matters. The new processes that CSSIW is introducing from 1 April 2012 (paragraph 26, final bullet) will clarify CSSIW's role and remit for handling complaints.

ENDS

¹³ These figures relate only to planned inspection visits and not to other visits that can take place between formal inspections, for example to follow-up on inspection findings. CSSIW's information systems cannot provide details of the total number of visits undertaken across all settings.

Agenda Item 4b

Health and Social Care Committee

HSC(4)-13-12 paper 6

Public health implications of inadequate public toilet facilities - Letter from the Communities, Equality and Local Government Committee

Attached as an annex to this paper, please find attached the response from the Communities, Equality and Local Government Committee to the Report by the Health and Social Care Committee on the evidence it received on the public health implications of inadequate public toilet facilities.

Committee Service

Pwyllgor Cymunedau, Cydraddoldeb a
Llywodraeth Leol

Communities, Equality and Local Government
Committee

Mark Drakeford, AM
Chair, Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
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Bae Caerdydd / Cardiff Bay
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20 April 2012

Dear Mark

Health and Social Care Committee – Inadequate public toilet facilities

Thank you for your letter of 5 March, in relation to the Health and Social Care Committee's inquiry into public toilet facilities.

The Communities, Equality and Local Government Committee considered and noted the contents of your report in its meeting on 15 March 2012.

Given that the evidence you collected suggests that there is a case for further investigation of local authority provision of public toilet facilities, I will be writing to the Minister for Local Government to make further inquiries in relation to this issue.

I will, of course, provide you and the Health and Social Care Committee with an update once the Minister's response is received.

Yours sincerely

Ann Jones AC / AM
Cadeirydd / Chair

Croesewir gohebiaeth yn y Gymraeg a'r Saesneg / We welcome correspondence in both English and Welsh
Pwyllgor Cymunedau, Cydraddoldeb a Llywodraeth Leol / Communities, Equality and Local Government Committee
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Chair
Health and Social Care Committee
National Assembly for Wales

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Ref: 40SOS 12

19 April 2012

Dear Mark

Thank you for your letter of 12 March.

I am grateful to you for keeping me informed about the work your Committee is undertaking into residential care for older people.

I have read with interest the written evidence submitted by the Older People's Commissioner for Wales, as well as the transcript of proceedings of 23 February when the Commissioner appeared in front of the Committee.

I have had a very positive working relationship with the outgoing Commissioner who has provided me with invaluable advice on the views of older people in Wales about the issues affecting them. I am pleased the Committee had the opportunity to hear first hand from Mrs Marks and appreciate the role the Committee is also playing in raising the profile of key issues around residential care for older people in Wales.

Turning to your view on the possibility of a Convention on the rights of older people, the Government is not convinced of the need for a specific UN Convention on the Rights of Older People. There are existing mechanisms aimed at ensuring older people's rights, including the Universal Declaration for Human Rights, the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), the Convention on Social and Political Rights, and the Madrid International Plan of Action on Ageing (MIPAA). We believe that these existing instruments contain all the basic



requirements to ensure the rights of older people and our priority is to ensure that they are enforced and respected.

It is worth noting that those pressing for a Convention do not take in to account the different definitions and requirements of ageing societies around the world and many of the concerns raised are regional rather than global issues. It is a relatively small number of countries who are in favour of a Convention – the majority of the UN Member States believe that a new instrument would only duplicate efforts. Alternatively, a coordinated approach across all Member States to enforce MIPAA would offer stronger support.

I look forward to the Committee's Report on its Inquiry in due course. I would be grateful if you could ensure I am provided with a copy of the final report once available.

Ys sicely

Rt Hon/Y Gwir Anrh. Cheryl Gillan MP/AS
Secretary of State for Wales
Ysgrifennydd Gwladol Cymru

Health and Social Care Committee

HSC(4)-13-12 paper 8

Correspondence from the Petitions Committee: Petition P-04-359 Problems with the NHS for the Deaf

Attached as an annex to this paper, please find attached correspondence from the Petitions Committee regarding Petition P-04-359 Problems with the NHS for the Deaf.

Committee Service

Y Pwyllgor Deisebau Petitions Committee

Mark Drakeford AM
Chair, Health & Social Care Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Bae Caerdydd / Cardiff Bay
Caerdydd / Cardiff CF99 1NA

Our ref: P-04-359

19 April 2012

Dear Mark

Petition: P-04-359 Problems with the NHS for the Deaf

The Petitions Committee has recently been considering a petition relating to problems experienced by NHS patients with hearing impairments. The petition called on the National Assembly 'to urge the Welsh Government to provide a better service for the hearing impaired (HI) in the NHS' and collected 68 signatures.

Supporting information submitted with the petition described the difficulties faced by a person with a hearing impairment when trying to book a GP or hospital appointment, or an interpreter and raised concerns regarding the lack of hearing loops in hospitals and the way in which hearing impaired patients in waiting rooms are called in to appointments.

The Committee wrote to the Minister for Health and Social Services on this issue. In her response, the Minister described the work that had been done on this issue and stated that a delivery plan would be available in the spring that would take forward the recommendations of the 'Accessible Healthcare for People with Sensory Loss in Wales' report that was launched on 9 January this year.

Given the work being done in this area, the Committee agreed to close the petition and to write to you to highlight the matter and ask that you keep a watching brief on the work being done on this important issue.

Yours sincerely

A handwritten signature in black ink that reads "William Powell". The signature is written in a cursive style with a large, prominent 'W' and 'P'.

William Powell
Committee Chair