



Cynulliad Cenedlaethol Cymru **The National Assembly for Wales**

Y Pwyllgor Iechyd a Gofal Cymdeithasol **The Health and Social Care Committee**

Dydd Mercher, 2 Mai 2012
Wednesday, 2 May 2012

Cynnwys **Contents**

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

Ymchwiliad i Ofal Preswyl i Bobl Hŷn—Tystiolaeth gan Gynghrair Henoed Cymru
Inquiry into Residential Care for Older People—Evidence from Age Alliance Wales

Ymchwiliad i Ofal Preswyl i Bobl Hŷn—Tystiolaeth gan y Gymdeithas Alzheimer's a
Parkinson's UK Cymru
Inquiry into Residential Care for Older People—Evidence from the Alzheimer's Society and
Parkinson's UK Cymru

Papur Gwyn ar Roi Organau—Sesiwn Friffio Ddilynol gan Swyddogion Llywodraeth Cymru
Organ Donation White Paper—Follow-up Briefing from Welsh Government Officials

Papurau i'w nodi
Papers to note

Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynddi yn y pwyllgor. Yn ogystal,
cynhwysir cyfieithiad Saesneg o gyfraniadau yn y Gymraeg.

These proceedings are reported in the language in which they were spoken in the committee.
In addition, an English translation of Welsh speeches is included.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Mick Antoniw	Llafur Labour
Mark Drakeford	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Rebecca Evans	Llafur Labour
Vaughan Gething	Llafur Labour
William Graham	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Lynne Neagle	Llafur Labour
Lindsay Whittle	Plaid Cymru The Party of Wales
Kirsty Williams	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats

Eraill yn bresennol
Others in attendance

Val Baker	Parkinson's UK Cymru
Nick Bennett	Prif Weithredwr, Cartrefi Cymunedol Cymru Chief Executive, Community Housing Cymru
Richard Davies	Prif Weithredwr, Grŵp Tai Gwalia Executive Director, Gwalia Housing Group
Dr Grant Duncan	Llywodraeth Cynulliad Cymru Welsh Assembly Government
Steve Ford	Prif Weithredwr, Parkinson's UK Cymru Chief Executive, Parkinson's UK Cymru
Kevin Hughes	Cyfarwyddwr Gofal a Chymorth, Grŵp Tai Pennaf Director of Care and Support, Pennaf Housing Group
Dr Chris Jones	Llywodraeth Cynulliad Cymru Welsh Assembly Government
Rachel Lewis	Swyddog o Gynghrair Henoed Cymru Age Alliance Wales Officer
Sue Phelps	Cyfarwyddwr Cymru Dros Dro, Cymdeithas Alzheimer's Acting Director for Wales, Alzheimer's Society
Chris Quince	Uwch Swyddog Polisi, Cymdeithas Alzheimer's Senior Policy Officer, Alzheimer's Society
Angela Roberts	Dirprwy Gadeirydd, Cynghrair Henoed Cymru Vice Chair, Age Alliance Wales

Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol
National Assembly for Wales officials in attendance

Sarah Beasley	Clerc Clerk
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Steve Boyce	Y Gwasanaeth Ymchwil Research Service
Llinos Dafydd	Clerc Clerc
Catherine Hunt	Dirprwy Glerc Deputy Clerk
Meriel Singleton	Clerc Clerc
Joanest Jackson	Uwch-gynghorydd Cyfreithiol Senior Legal Adviser

*Dechreuodd y cyfarfod am 9.01 a.m.
The meeting began at 9.01 a.m.*

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da a chroeso **Mark Drakeford:** Good morning and
ichi i gyd i'r pwyllgor. welcome to you all to the committee.

[2] We are ready to start the session. Other Members will be along in the first few minutes, I am sure. Thank you all very much indeed for coming to help us with our inquiry into residential care for older people. In this first session, we are concentrating on evidence from third sector providers in this field, and we are interested in particular in talking to you about different models through which residential care services might be provided. Just so that Members know who everybody is, let me introduce Nick Bennett, the chief executive of Community Housing Cymru, Richard Davies from Tai Gwalia, and Kevin Hughes from Tai Pennaf. Welcome to you all.

[3] Diolch yn fawr ichi i gyd am ddod. Thank you all very much for coming.

[4] We normally give witnesses a few minutes at the start of the meeting to introduce the evidence, which we will already have had a chance to read. I will then move to Members for questions. With a bit of luck, if there is a minute or two at the end, I will come back to you in case there are any points that have not emerged strongly enough in the evidence that you want to reinforce with us. Nick, are you going to lead off?

[5] **Mr Bennett:** Yes, I will. Diolch yn fawr. We really welcome the committee's review of this. You will have been bombarded, I am sure, with all kinds of startling statistics about the ageing population and the impact that it will have on devolved and, indeed, non-devolved policy making. One in two people born this year will reach the age of 100 and, by 2033, one third of the population will be over 65. In 1917, George V had to write 24 telegrams to people who had reached the age of 100, but whoever is on the throne in 2033 will have to write 40,000. Obviously, there is a huge demographic there. Just last week, there was another public service reform meeting in north Wales where it was claimed that the cost of additional care for the ageing population over the next decade will equal the amount that the Whitehall administration is trying to save as part of deficit reduction. The demographic is that big, and it really does raise the question of how we cope with that type of change.

[6] Some registered social landlords have started to respond to that social market, not through any political imperative, but as social enterprises that have seen a social need and responded to the opportunity. That is why I am glad to be joined by Kevin and Richard as, between them, Gwalia and Pennaf provide services across Wales. Of more than 40, about four RSLs have really looked into the potential for residential care, but there is a deeper interest in

the care agenda more broadly. We have 22 Care and Repair agencies in Wales and their rapid response programme helps to save £7.50 for every £1 invested in the NHS. We have felt for the last few years that there is a lot more that we could do to mainstream the work, which has really grown up from organisations such as Pennaf and Gwalia.

[7] We commissioned a report from the Kafka Brigade some 12 months ago, and we are happy to share it with the committee. It informed the response that we sent in. It raises a number of issues that we think go with the grain of the 'Together for Health' strategy about keeping people out of hospitals, and if they are in hospital, helping them through reablement to get back home. We launched it jointly last November with the Minister for housing and the Minister for health at an event in Newport. It has led to more joint working in the Aneurin Bevan Local Health Board area, and we will be having a meeting with the LHB in the middle of May to look specifically at what greater joint working we could do around mental health and frailty. We hope to do something similar in north Wales, where we will be meeting with the LHB on that subject in the middle of the month. However, I would have to say that there is huge potential there. We should be doing more. This document talks about the potential for expanding not-for-profit residential care, increasing the number of services provided through extra care and sheltered housing, and how that could help with the £30 million per year that is currently lost to the NHS through bedblocking. We think that there is a lot more that could be done there. Our message to the committee more generally—and we discussed this before we came in—is that there is a job of work to be done on silo smashing, and ensuring that there is a more citizen-sensitive approach for the future. The cultures of health and housing are different—the accountabilities are in separate silos, and that means that there is almost a constant challenge to bring those barriers down and provide cheaper but higher quality services for increasingly older citizens in Wales.

[8] **Lindsay Whittle:** In another life, I was leader of Caerphilly County Borough Council, and there is much emphasis on local authorities working with health authorities and sharing budgets. Could you outline how registered social landlords work with health authorities and social services?

[9] **Mr Hughes:** Perhaps I will start. Tai Pennaf operates primarily in the north and in mid Wales, and I would have to say that it has been challenging with Betsi Cadwaladr University Local Health Board. The chief executive of that authority is not currently there, but in the early stages we met with its senior management team, who were very receptive to meeting us, as a housing association, and the message that they gave us was that they wanted to work more flexibly and imaginatively, with more formalised structures in local authorities. For example, I sit on Conwy County Borough Council's older person's strategy working group, and therefore there is a tangible link with care from the landlord's relationship with the local authority. It is an emerging relationship with the Betsi Cadwaladr trust. We have to continue to indicate to it that we believe that we have a fundamental role to play in some of the challenges that it faces. For example, we have just opened a new nursing home in Colwyn Bay, which is near Ysbyty Glan Clwyd, the large district hospital, and we have a number of vacancies there. We have had dialogue from a very early stage about what we can do to assist them with any issues, such as delayed discharge. Those issues have been challenging, but the relationships are still emerging. So, in answer to your question, there is a much more formalised relationship with the local authorities to the point that we are heavily involved in key strategy documentation and in planning the services. So, the relationships are emerging with the new health boards.

[10] **Mr Davies:** Tai Gwalia works across south and mid Wales and we have a range of relationships with local authorities and health boards in different client group areas. This is not just about what we do in housing because we are a major care and support provider. All our contracts are with local authorities and health boards, either through social services or through Supporting People. Experiences can vary, but we have some positive examples of

working well with those statutory agencies. We feel that, because we work so widely and provide both housing and care and support, we have a lot to offer in trying to understand the strategic challenges. Often, some of our more positive experiences have occurred when we have worked well with commissioners on developing these services. However, at the same time, that is also when we have felt frustrations over procurement rules or when the strategic relationship is not taken as far as we think it could be taken within the parameters, to allow us to offer solutions to what are strategic problems for us all, whether keeping people out of hospital or developing better community services. So, it is a bit of a mixed relationship, but the lights are on and there are some positive examples.

[11] **Lindsay Whittle:** Are there any examples of shared budgets yet?

[12] **Mr Davies:** We have seen some positive examples of that working in different client group areas. We have just had positive experiences in the Swansea, Neath Port Talbot and Bridgend areas relating to learning disability, where we have been commissioned to develop services to allow people to be repatriated from expensive out-of-area placements or out-of-Wales placements. Health and social services have worked very well, bringing their budgets together to achieve that. In Cardiff, we are developing a service that is a step down from a low secure mental health service, on which we have worked well with the Cardiff and Vale University Health Board and Cardiff's social services. So, there are good examples out there, but there are also clear barriers and difficulties.

[13] **Rebecca Evans:** I am particularly interested in services and support for marginalised older people. We have heard some evidence that people who have offending behaviour or have drug and alcohol-related issues or lesbian, gay, bisexual and transgender people and ethnic minority groups might be particularly poorly served by what is available at the moment. What extra care is available and is needed for people who fit into one of these marginalised groups?

[14] **Mr Davies:** That is an issue and, again, it is about how we, as providers, can be more flexible about how we meet particular needs. For example, I have been working with the Swansea Chinese community on issues that they are raising about older people in their community, and the cultural barriers and language issues that they face when they go into mainstream nursing or residential care. So, that has made us think that much of this is about how you design buildings that are culturally sensitive. You can be flexible about this, and good design can meet a whole range of different needs. You could take their issues into account. However, much of this is also about relationships, and how people relate to one another and are sensitive towards each other. Values are at the heart of everything that we do as the sector organisations. It is about how our staff are trained and supported and how they then relate to the individual.

[15] There are issues for people who have particular needs. We have had conversations with commissioners about older people who have alcohol problems increasingly becoming an issue. We have also worked with offenders and people who have been on drugs. We must consider how best to support older people with those needs. It is about models of accommodation and of support in community that are most important, along with how you train people. This is all about values and relationships at the end of the day. That needs well-run, value-driven organisations. How we do that is the key to it. There is no magic solution; it is how you support people where they are in the most appropriate way, and working with the other agencies that support them.

9.15 a.m.

[16] **Rebecca Evans:** We have heard in our evidence that it is important for people in housing-based care and residential care to be able to access the community that surrounds

them. Are there issues about people in these more marginalised groups being further marginalised, if you like, because the local community might be unwelcoming, because of the challenges that it might face? If so, how do we address that?

[17] **Mr Hughes:** The challenge for us as landlords, bearing in mind that we all have strong values, is to find flexible solutions. I agree with Richard that you can design holistic services to meet a variety of needs. For example, we have worked on a scheme in Wrexham, where there was a specific need for a service for homeless people from the Polish population. We designed the service particularly in response to that, because the Polish clients could not speak any English, and there were specific needs. So, we can show flexibility, but we are increasingly evaluating the communities that we work in, trying to engage with other partners, determining what services they need, and trying to design our schemes so that they are much more holistic and flexible. There are various solutions, and it is always about looking for solutions.

[18] **Mr Bennett:** The Kafka Brigade report, which we will make available to you all, talks about the concept of the mutual care village. It is a specific attempt to look at more creative, community-based solutions, given the demographic trends to which we referred earlier.

[19] **William Graham:** Thank you for your paper. Could you enlarge a bit on the potential for extra care schemes, and note any particular barriers to funding?

[20] **Mr Davies:** We already run three extra care schemes, and we are looking at how we can extend that model. Again, the critical point that we keep coming back to is how people are supported within that environment and how flexible the care and support is, whatever the environment may be. Extra care schemes can be very positive if they are well designed. The quality of accommodation is important, and there is a ready-made community there, so that people can be supported to integrate into communities and maintain their lives. That is critical. One issue that came up for us, particularly in relation to dementia, which is critical to what we are talking about here, is how people are sustained within their environment. There is a tendency to think too much in silos—nursing, residential, extra, sheltered, or at-home care. What matters is that the person can see for themselves and that you are able to support and sustain them in that environment. The same is true in extra care. As the needs increase, there is no reason why we cannot keep supporting that person for as long as possible within that environment. There may be an issue around how we support people better in sheltered accommodation. There is definitely the ability to use that model positively.

[21] I do not want to make this too much of a mystery: at the end of the day, extra care is homecare. That is how I describe it to people. It is personal care support, but it just so happens to be called ‘extra care’. It is the same thing. We train our staff to give the right level of personal care to someone, wherever they are, and to try to sustain them, as well as to be able to step that up, if necessary, for as long as possible, with health service support or whatever. Funding-wise, across these range of options, we are here because we are also involved in residential care and nursing home care, and it would be worth exploring how funding support might be able to supplement our approach to raising money privately.

[22] **Mr Bennett:** One specific pressure on extra care is what is happening with capital funding, and the 40% cut that the Welsh Government faces over the next three years following the comprehensive spending review. The CSR took £120 million out of social housing investment over the next three years. We are pleased to see £30 million coming back in through consequentials during the course of this financial year; we did not see that coming, and it means that the level of cuts to the social housing grant is £8 million this year rather than £40 million, which is a good outcome. Further to the comment about not seeing it coming, it is difficult to plan to ensure that we are providing the most significant capital schemes in the

right places, particularly for extra care, if we do not know more than one year ahead from where the additional investment is going to come. We have called for that gap of £120 million to be plugged. There will be an opportunity for that to happen with the supplementary budget and the most recent consequential of £220 million that has come to the Welsh Government following the October statement.

[23] Even from a not-for-profit perspective, we want to do more. We have made an offer to the First Minister, the Minister for Housing, Regeneration and Heritage and the Minister for Finance, asking whether it is possible and appropriate, certainly with regard to education, to use registered social landlord borrowing powers to ensure that there is some provision for shovel-ready schemes that would not otherwise go ahead because of the economic environment. The same might be true under certain circumstances for health-related projects as well. You currently have an NHS capital budget of £400 million, which is being disaggregated on 100% grant funding. On social housing, you were disaggregating £100 million a year, but that was leveraging in at least another £100 million in additional private funding. All of that is under mutual control. If mutualism or social enterprise, co-operatives and others are part of a more creative solution, given the austerity that is on its way, there is a lot more that we could do to use the RSL model to scale up capacity. We might not necessarily be doing more with less, but we could do a lot more with the same.

[24] **Mr Hughes:** I wish to mention the sustainability factor. We are looking for ways to develop a range of services without using grants. We have a long-established relationship with the banks, which is built on strong governance and robust approaches to how we manage our finances. There is a lot of regulation, which makes us attractive. We can, therefore, go to the market, and we are driven to develop more services. It happens through a combination of routes; it is done through the grant route, and doing more that way, as Nick has indicated, and through non-grant routes. That is how we are developing into the nursing care sector in particular.

[25] **William Graham:** In your paper, you mention the possibility of an increase in self-funding. Is that challenging or productive for you?

[26] **Mr Bennett:** Do you mean self-funding with regard to the individual carer or the association?

[27] **William Graham:** I meant the individual carer.

[28] **Mr Davies:** We have to look at affordability. We exist as organisations that are trying to support people in greatest need, so that is always our focus. It is also the challenge, in terms of being able to deliver services that are affordable and viable, because we have to achieve those things as well. The top-up is a common approach across the private sector; it happens all over the place, so it is not something that we cannot say that we cannot look at. However, we come at it from the perspective that the people in greatest need are why we exist; that is our thought process, but it does not mean that we do not look at the other issues as well.

[29] **Mr Hughes:** The issue for us is how receptive our colleagues in the health service and local authorities are to entry into formal contractual arrangements with us. If we can get some security of service delivery, it makes our ability to deliver a product without introducing third-party top-ups much greater. One of our schemes in Chirk is going to be changed from a 35-bed care home to a 76-bed elderly mentally infirm specialist provision facility. We have had positive discussions with the local authority there, and we have entered into a block contract arrangement. In terms of going to the market, that contract gives assurance and makes it sustainable in terms of our financial planning, without us having to introduce third-party payments. While third-party payments may be inevitable, our aim, as social landlords, is to base our modelling on trying to provide the service at the rate that local authorities and the

health service pay.

[30] **Mark Drakeford:** Professor Bolton said to us that he thought there was a case for more extra care facilities being put up for sale, rather than on a rented tenancy basis, in the sense that William was asking you about more self-provision in the system. Do you see that as a possibility in Wales?

[31] **Mr Hughes:** The for-sale model was designed by our director of finance in consultation with the Welsh Government. The dilemma has been build costs against market values; they are some of the challenges that we have to face. In our designs, we are constantly looking at build costs. The market changed. Anybody can buy in our schemes: they can buy into our service, but the market has changed. Therefore, in terms of the models that we are looking at, for the future we are looking at design space standards: some of them are very big and there can be expensive build costs. So, we are forever reviewing and we are flexible enough to review the model based on how the market is.

[32] **Mr Davies:** We would go along with that—[Inaudible.]—flexible in the models that we put together. On design, one of the things that characterises what we try to do, in terms of the development of our services for older people, is the quality of design. One of the things about who we are as a sector and organisations is that we want to be driven by the best possible standards in those areas. Obviously, there is a cost balance that one has to achieve. However, we are particularly focused on trying to advance the quality of design for people with dementia, particularly. That is characterising what we do, and will influence what we will, and will not, build.

[33] **Mick Antoniw:** I would like to explore some of your written evidence with regard to ownership models and the not-for-profit or mutual sector versus the private sector—and I am not counterpoising them. However, on the balance that we have at the moment in terms of provision, there are indications that although there is variability, the majority of provision is private or corporate in one form or another. Do you have any views on the impact of that balance? Do any issues arise from the current balance? Is there any reason why we should want to look at that?

[34] **Mr Bennett:** Yes, but I would say that, would I not, as we obviously represent not-for-profit providers? However, there is a strength to the model, which I think that Kevin has already alluded to. First, can we access cheap private finance? Yes, we can, and that is quite an advantage at present, given the behaviour of the banks and the difficulties that small and medium-sized enterprises and others are having in accessing cash. The costs and the risks are lower and there is not the same pressure and hot breath from shareholders to achieve value in other areas through, perhaps, driving down labour costs and so on, which means that, for the same level of cost to the consumer, you can sustain a better quality of service because you are not trying to provide that return to the shareholder. Going forward, with the pressures of an ageing demographic, there will be a lot more value in that level of service.

[35] **Mr Davies:** The other thing I would add to that is that our focus also is not on particular parts of the continuum, but on the whole continuum, and on our ability to finance, design and build things and deliver care and support with an integrated person-centred approach. Certainly, that characterises what we are doing. So, we will be a provider of nursing homes, residential care, homecare, extra care and sheltered housing in a particular area of Wales, and we think that that is important, because it allows us to build capacity, and it allows us to be more responsive and flexible in how we treat and develop our staff and how we deploy them, particularly as we get into the world of personalised budgeting and direct payments and so on. So, that is the type of model that we are seeking to develop. The key thing about the strength of our approach, from a third sector perspective, is partnership. We should be able to broker partnerships and work well in partnerships with others to make a

more coherent service in particular areas.

9.30 a.m.

[36] **Mick Antoniw:** If you had to summarise, what would you say are the main differences with the not-for-profit sector for the future? You talked about the interaction of services and development. Is that a strength of your sector? Is that not something that is also perfectly possible in the private sector?

[37] **Mr Bennett:** It can happen in both places, but the theory would indicate that it would be achieved in a different way. When Richard refers to partnership, it is also about having a participative model. I know that there is no agreed definition of a social enterprise, but I will go with the Wikipedia definition, which says that you must be providing a good or service of some description, have social aims and a certain level of social ownership. The social ownership is all-important here. Typically, one third of the board of any registered social landlord would be made up of service users, whereas with a private sector approach you may have a less visible hand in the market, to misquote Adam Smith. So, there is a direct input with a social enterprise model that I do not think you get from private providers.

[38] **Mick Antoniw:** If you could make one or two key recommendations to the Welsh Government with regard to how it might develop or support the not-for-profit sector, what would those be?

[39] **Mr Bennett:** First, we must have an awful lot more engagement between the health sector in Wales and the not-for-profit sector, which is an ironic statement to be making in an Assembly, given that the NHS was born from the Tredegar Medical Aid Society. It all started with mutualism, did it not? Yet we seem to have got ourselves into a position where there is this significant division between the NHS and its not-for-profit partners. That does not mean to say that good things do not happen, but we are not maximising the return to the taxpayer or the citizen. We could be a lot more ambitious.

[40] There are also a number of myths that can prevent proper partnership working. Kevin has already alluded to procurement, not just in the area of health, but in other areas as well. I am sure that advice often goes to Ministers saying that they cannot do this, that or the other because there is an EU treaty that does not allow them to procure in that way. That can percolate down and create nervousness on the part of procurement professionals in the NHS with regard to having the sort of dialogue that you need to have with your not-for-profit provider so that you can provide the best possible service locally. We have taken legal advice on this, but for other issues not to do with health or social care. There are at least three different opt-outs from EU treaties when it comes to public authorities engaging with not-for-profit providers, and yet we still come up against this brick wall. An awful lot more could be done. That is probably more a corporate issue. It is not just a health issue; it comes up in other areas.

[41] With the Kafka Brigade UK report, which comes from a consultancy that claims it can break through bureaucracy, we think that we have provided a series of ideas that would scale up not-for-profit residential care and make much better use of sheltered housing and extra care provision so that we can do something to save the £30 million that is wasted through bedblocking in Wales every year. It also contains a number of ideas that would help the citizen to stay in their home or to be re-enabled. It takes them out of the hospital setting and works with the grain of 'Together for Health'. Therefore, with regard to overall policy objectives, I cannot see any conflict between this report and the strategic direction of the NHS.

[42] **Mr Hughes:** Another issue for me is that we should not reinvent the wheel. We

believe that we are already well placed to provide flexible and imaginative solutions and services. We are very fortunate in Wales in that we are very flexible. We can respond to each other's very positive relationships. It is about communication and getting these relationships working, but not to create anything else when there are already mechanisms in place that can deliver on a whole range of topics.

[43] **Darren Miller:** Could you expand a little on the differences between private enterprises and the not-for-profit sector in terms of the quality of care that is provided? As far as I understand, the quality is fairly consistent no matter who provides the care in Wales. That is the evidence that we received from the inspectorate. It stated that different models of ownership do not typically affect the quality of care provided. Is that what you understand to be the case? I noticed that evidence we received from Cymorth states:

[44] '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'.

[45] I just wonder what the basis of that feeling is and whether you support the comment that there are higher standards of care and dignity as a result of being not for profit.

[46] **Mr Bennett:** First, I think that the Cymorth paper endorsed our evidence. Therefore, I fully endorse the Cymorth position. We did not come here with a higher moral tone, to say that we are simply better than the private sector because we are different. However, I wish to point you towards two specific characteristics that should be very different from a social enterprise model rather than a private model. The first is cheaper access to capital, which, I think, has probably become a much more acute issue, perhaps, for some of the private providers following the credit crunch, as it has done throughout the private sector. The second is the issue of social ownership and the fact that for a not-for-profit model to work, it has to engage with end users. That is my perspective, in terms of theory, but in terms of practice, perhaps Richard and Kevin would like to comment.

[47] **Mr Hughes:** I will give you a practical example for the purpose of illustration. You have reflected on CSSIW in terms of a general evaluation of the service, but in terms of the accountability dimension, we run a number of care homes and the expectation is that we reach high standards of excellence at every inspection. If I do not, there is a whole range of accountabilities and processes that I need to demonstrate. While the general picture might be that there is no evidence, I would suggest to you that, in terms of organisations like ours, the expectation would be for us, through governance, to provide high standards. We do that by being imaginative in the way we deliver services. For example, we recognise there is an intrinsic link between positively trained staff and—insofar as we are able—well-paid staff. Our approach on pay is to pay the median in the market, not the minimum wage. Our terms and conditions are favourable. The outcome of that is that we believe that we get good delivery as a result. I respect your view in terms of the CSSIW's general evaluation, but in terms of some of the governance stuff around where our board sits and expects—

[48] **Darren Millar:** To be fair, there are examples of good governance in the not-for-profit sector and in the private sector, and there are examples of bad governance in both sectors. We all know what is currently happening with organisations like AWEMA and so forth. Obviously, they are not housing associations, but clearly there are issues of governance, no matter what type of organisation they might be. I still do not understand—

[49] **Mr Bennett:** On that point—

[50] **Darren Millar:** Just a second; I still do not understand how you can defend a statement that states that there are higher standards of care in the not-for-profit sector than there are in the private sector when there is absolutely no basis or evidence to suggest that that

is the case according to CSSIW, which does the inspections.

[51] **Mr Bennett:** Kevin has already pointed to the nuance within the CSSIW—

[52] **Darren Millar:** He said that the governance is better.

[53] **Mr Bennett:** To be clear, in terms of the double lock, although it is probably a treble or quadruple regulatory lock, in terms of RSL provision when it comes to care. First, we have the new governance system that emerged from the Sue Essex review, which looked specifically at good governance and the financial viability of every housing association in Wales. That is conducted annually. The most recent results were published just last month, which gave a clean bill of health to every registered social landlord in Wales. Clearly, that is a discipline that would not be available to Southern Cross, for example.

[54] We also have the fact that a number of RSLs in Wales are also accountable to the Charity Commission because they are either a charity or, in many ways, they are independent service providers that have charitable rules. On top of that, they have their own boards, which will be exercising good judgment and governance, and they are doing that on a not-for-profit basis, which draws from end users. Typically, a third of an RSL board will be made up of tenants. So, between those different factors, you have a multidimensional quadruple lock of regulation that you simply would not get in the private sector, where it would just be down to the Care and Social Services Inspectorate Wales.

[55] **Darren Millar:** Obviously, you have the CSSIW boards and, of course, you have Companies House. I want to ask a final question, if I may. You have paid a lot of attention to emphasising the fact that end-service users are on boards of housing associations and RSLs, and I understand that and it is something that I welcome. What proportion of those are service users of residential care in any of your organisations? Is that something that you can provide the committee with?

[56] **Mr Davies:** We could provide the information.

[57] **Darren Millar:** I am not aware of any organisations that have residential care users on their boards.

[58] **Mr Davies:** Our sector's involvement in residential care is developing. We are not managing a high number of residential care homes. However, the models of how we are involving those people in the governance of our services are developing positively. One example that I wanted to give you was Gwalia's recent transfer of Neath Port Talbot's eight residential care homes for older people. The positive experience of that in direct relation to what you are saying is that we have established an older adults committee and will have representation from elected members of Neath Port Talbot, if they feel that to be appropriate, and innovative ways of listening to residents and including them in our decisions about improving the care. So, we can answer the question directly about the numbers, but there are only so many homes that we are currently involved with.

[59] **Darren Millar:** I have seen evidence of good practice in residential care homes in the private sector where they engage service users in the development process.

[60] **Mr Davies:** Absolutely.

[61] **Mark Drakeford:** It would be useful if you are able to provide that specific piece of information.

[62] **Mr Hughes:** I will also provide some information for you, to demonstrate that

service users are at the heart of the service planning.

[63] **Mark Drakeford:** Thank you. We certainly know that it is not easy. This committee has a reference group that is working with us on this inquiry, and we were not able to recruit a single person directly as a resident of residential care as a member of that group. So, no-one is suggesting that finding people in that position and who are able to do that representative job is an easy thing, but it would be interesting for us to know.

[64] We will take questions from Elin next, and then Vaughan.

[65] **Elin Jones:** I want to go back to the relationship and the work that can be developed between registered social landlords and the national health service. You refer in your evidence to your interest in developing work on early discharge schemes and preventing people from entering hospital in the first place. I was wondering whether you have examples of where that relationship has worked well—I think they may be few and far between. You also make specific reference to the fact that the NHS, in particular, is keen to have access, on an ad hoc basis, to beds that you may be able to provide for early discharge but are not able to block book in advance, which would give you the ability to plan and work with the service in a more structured way. How would you like to see your relationship with the NHS and social services developing? How could that work in a more structured way? Obviously, budget plays a role here. I was also wondering whether regulation has a role in this, because, if I am right, extra-care schemes are not regulated by CSSIW.

[66] **Mr Davies:** That is domiciliary care.

[67] **Elin Jones:** Perhaps you could explain that to me—how is that a barrier, or otherwise, to that co-working?

9.45 a.m.

[68] **Mr Bennett:** First, the overall policy message here is that, for a country where the NHS grew out of mutualism, there should be better engagement between the NHS and mutualism, particularly given the additional demographic pressures that will emerge for all forms of public service. As we said earlier, experience has been patchy and perhaps it needs to be more uniform. Myths have emerged in terms of what can and cannot be done by the Welsh Government, its procurement practices, the NHS and third sector providers. There is perhaps an opportunity—is it the McLelland review of procurement policy in Wales that has been commissioned by the Minister for finance? It would be useful if that could look at aspects around procurement with the third sector, because it should result in better outcomes for citizens and end users and build capacity, which is our real aim here. The fact is that you could increase capacity but retain control through mutualism and regulation in the third sector and ensure that there is accountability to the citizens, rather than to shareholders. That is the point that we are really trying to emphasise. I do not have a clue about the detail between CSSIW and the other aspects of regulation.

[69] **Mr Davies:** The issue around procurement and being able to work creatively with providers would help. There are issues, as you alluded to, with the NHS not being able to commit to block booking beds; I know that Kevin has an example of that. We currently have an example of that where we are building a nursing home in Carmarthenshire and we will not get that agreement. As any developer has to do, we then have to be more prepared to take risk and develop things at risk. Another example is in the mental health field in south-east Wales, where we are building a step-down facility from the low secure unit in Cardiff and we are seeking to develop a woman-only service that would cover three health board areas, because we know that the need is there. It is clear and it is evident. We have talked to clinicians and managers about it and we know that a good-quality environment to deliver that would be

welcome across those health board areas, but we are not going to get a block contract. We will need to have established it, set it up and taken that risk. That is how it is. I suppose that the procurement issue is at the heart of that.

[70] This is not just about health, but about health and social services. The two areas are often intertwined, and the relationship between the funding is critical. We feel that we have a lot to offer as organisations working right across Wales. We have different experiences with different commissioners in different areas, and where they are positive, we are able to develop services that can start to tackle some of these strategic challenges—keeping people out of hospital and maintaining people in the community. We are doing it through discussion and there are good examples in certain places, but there is no real form to it.

[71] **Mr Hughes:** It is a similar picture in north Wales. We cannot—[Inaudible.]—for a nursing home that is purpose built, brand new and in a nice area of north Wales, and we have 20 vacancies there. I have had dialogue with the board, and it has indicated that delayed transfers link to rehabilitation in community hospitals. Therefore, I have said, ‘Let’s discuss what a rehabilitation package looks like; we’re flexible enough, so we’ll deliver it. We’ll put in the resources of delivering that service’. It is about having that formal dialogue. This issue of procurement is worthy of some work so that people are clear that there is scope for us to be flexible collectively in this area.

[72] **Vaughan Gething:** I want to go back to some of the earlier points, particularly those that you made in your opening remarks, because a number of us have undertaken visits both to older residential care facilities and to some newer ones. What I found interesting was not so much the difference in the facilities in terms of co-locating extra, nursing, dementia and residential care on the same site, but, in particular, the difference in ethos between some of the newer and older homes. I am interested in going back to some of the drivers for not just needing to think about provision for the future, but about the change in the type of provision, and how much of that is simply population, demand or market led, because more people will live longer, how much is led by regulatory change and how much is about choice and best practice in terms of what provision should be available. The fourth point concerns the role of commissioners, and whether local authority commissioners for residential care and other types of care are coming to you and saying that they want something different. How does each of those fit in with the different sorts of provision?

[73] **Mr Bennett:** To reiterate the point, there has been no direction from the NHS or from the housing directorate for RSLs to diversify into residential care. They have done it because they have seen a demographic need and an opportunity, not to make profit, but to make a surplus, which is reinvested in more services, more not-for-profit care regeneration and housing. I think that that could probably continue—I am sure that it will, and that we will see more social enterprise entrants in the market and, perhaps, an expansion. On the way in, Kevin was telling me that, in his social business, staff numbers have increased from 80 to over 400. Again, none of this has been because of some kind of Government direction; it has been in response to demographic change, and I am sure that that will continue.

[74] Perhaps the issue here is that if there was a more receptive environment when it comes to engaging with the NHS and public authorities, we could achieve more value. The feedback that I get from members, day in and day out, is that it is often very difficult to engage with the NHS—it is a massive organisation; it almost feels like a government within a government. As we have alluded to, engagement has been patchy. In the next month, we will be sitting down with Betsi Cadwaladr University Local Health Board and with the Aneurin Bevan Local Health Board. With Aneurin Bevan, we are looking specifically at areas where we can make savings and create better services when it comes to frailty, mental health and bedblocking. That should be happening everywhere, I think. We are very willing; we want to do more. That is why we commissioned this research. We think that there are lots of ideas in

there that could really assist, particularly given the very real financial pressures that the Welsh Government will face over the next few years.

[75] **Vaughan Gething:** What about local authority commissioners and your relationship with them? We had some evidence from the Welsh Local Government Association and some local authorities, and it seems that there is an uneven picture for the level of progress, in terms of changing the nature of provision and, in particular, in engaging with people such as you—the registered social landlords.

[76] **Mr Davies:** I think that it is variable. It depends on which local authority you are in and what the pressures are on that particular local authority. There is also the funding issue, in terms of how they will approach the balance of care that they are seeking to achieve. A lot of it is clearly related to financial pressures and eligibility criteria being ratcheted up, so that it is critical and substantial need only, and that affects what can be delivered in that area.

[77] Our response to that is to say that we need to deliver a range of flexible services, and the issue of choice can then come into it. People can be supported better at home with a variety of support for as long as possible, and local authorities would place people in care homes if they were at the higher level of need. It is therefore forcing that more towards the nursing home model of care for those with a higher level of care needs.

[78] It is nonetheless variable. I mentioned our positive experience with Neath Port Talbot council over its residential and respite care facilities. The council put them out to open tender, and we were successful in that process, but it is a long-term contract—it is a 25-year contract—and that allows us to think about the re-provision of buildings that are not going to be up to registration standards, with enough time and resources to do that creatively and to a high standard. To us, that is a very positive example and a very different experience of working with a social services department that has come at it from that long-term perspective.

[79] **Vaughan Gething:** There is just one more thing on this point about commissioners and market planning. In his evidence to us, Professor Bolton has suggested that there should be what he referred to as market position statements from each local authority. We are talking about what needs are seen now and in the future to allow them and the people that they commission care from to plan. In its evidence to us, the WLGA told us that it would expect to provide something like that over the next 12 months. Have you had any engagement with local authorities in the planning, or have they engaged you by saying that this is what they are thinking about? How useful would you see that, as an exercise?

[80] **Mr Hughes:** It is patchy, but it is emerging. We have responsibility here, because, to me, the critical start of the identification of service provision is the strategy. If local authorities have inclusive strategies with major stakeholders, it is possible to model and develop that service. For example, in Conwy, we are at the centre of the older persons' strategy and we are talking about quite imaginative stuff in relation to joint commissioning with RSLs operating in the area and broadening the services to other RSLs and local authority housing. So, it is patchy, but there is an emerging picture. However, I would say that we have the opportunity to influence that. We are invited by local authorities to engage in strategy formulation.

[81] **Vaughan Gething:** Finally, how do you move from what you see as a patchy picture—which others have told us is patchy—and how would you recommend that we try to exert influence and provide a more joined-up, consistent picture?

[82] **Mr Davies:** The Neath Port Talbot example that I mentioned was very positive, because its programme to transform older people's services has been going for two or three years. This has not been quick. It has taken a very strategic view of this and has engaged with

service users, representatives and other organisations. That has been a very positive approach. It has been heavy on consultation and transparency and, as a result, there has been a major transfer under the Transfer of Undertakings (Protection of Employment) Regulations 1981 of 360 people and a transfer of 249 residents in 8 homes, which have both gone very well. There has not been much noise about that. That is to its credit and is due to the way in which it has managed that strategically. Bridgend has been talking to us and others about the development of its strategy. I do not think that it can be done quickly, but that is a good example and it is worth looking at. As to how you get that across the piece, there needs to be learning or it may be a structural issue.

[83] **Mr Bennett:** To hark back to the research that we commissioned, this calls for a strategic signal. You have to be absolutely serious about using language and you have to smash that silo. People within the health service have to realise that engaging with RSLs and the people involved in not-for-profit housing is not some kind of subversive activity; it can lead to better services. It is okay. *[Laughter.]* I think that a lot of value would come from the committee's work if that signal could be repeated once again. In fairness, we have had one joint session at which the Minister for Housing, Regeneration and Heritage and the Minister for Health and Social Services were present, and they certainly welcomed this work and challenged both sectors to do more together. However, some of the cultural differences are so deep by now that, to make an impact, you have to keep on repeating some of these signals until you are tired of the sound of your own voice.

[84] **Mark Drakeford:** I am afraid that we are well past the time that we have for the session, so we will not have a chance to ask you to sum up, but I think that you probably just did that, Nick. I will sum up myself by saying that there are bits of information that you will provide to us: we will have a copy of the Kafka report and you will let us have an answer to Darren's question about the direct representation of people in residential care on the boards of RSLs. Richard, it would be very useful to the committee, if the material is easily available, if we could have a look at information about the Neath Port Talbot experience, because you referred to it several times and it would be helpful for us to have a bit more background information on that. Nick, I have one very last question for you, to which I only want a one-word answer. A number of us went last week on a visit to a not-for-profit extra care development and it was put to us quite powerfully that there is a feeling that the not-for-profit sector needs a more distinctive voice in relationships with the Welsh Government and that, if the Welsh Government was in a more focused dialogue with the sector, it would provide a more useful forum for developing these things in the future. Is that something that you recognise or agree with?

[85] **Mr Bennett:** I think that that is why we commissioned this research. Members were giving us feedback that suggested that they felt that this was an area in which we need to make a much more distinctive offer. That has been proven. I am meant to be giving you a one-word answer, so I will say 'yes'.

[86] **Mark Drakeford:** Good.

[87] Diolch i chi i gyd am ddod yma'r bore yma ac am eich tystiolaeth, sydd wedi bod yn ddiddorol dros ben. I thank you all for coming here this morning and for your evidence, which has been extremely interesting.

10.00 a.m.

Ymchwiliad i Ofal Preswyl i Bobl Hŷn—Tystiolaeth gan Gynghrair Henoed Cymru

Inquiry into Residential Care for Older People—Evidence from Age Alliance Wales

[88] **Mark Drakeford:** Bore da a chroeso i'r tystion o Gynghrair Henoed Cymru. Diolch yn fawr am ddod y bore yma ac am eich tystiolaeth ysgrifenedig. Croesawaf Rachel Lewis, swyddog Cynghrair Henoed Cymru, ac Angela Roberts, y dirprwy gadeirydd. Rwy'n eich gwahodd i wneud rhai sylwadau agoriadol byr ac ar ôl hynny byddaf yn troi at aelodau'r pwyllgor i ofyn cwestiynau.

Mark Drakeford: Good morning and welcome to witnesses from Age Alliance Wales. Thank you for coming this morning and for your written evidence. I welcome Rachel Lewis, Age Alliance Wales officer, and Angela Roberts, vice-chair. I invite you to make a few brief opening remarks and I will then turn to committee members to ask questions.

[89] **Ms Roberts:** Good morning, Chair and committee. Age Alliance Wales is very grateful for this opportunity to meet with you. Today you get second best, because Sarah, our chair, has been appointed to a new post, so I am afraid that you get me, the vice-chair.

[90] Age Alliance Wales was set up in 2003 and is funded by the Welsh Government. It is a powerful alliance of 20 national voluntary organisations that are committed to working together to develop the legislative, policy and resource frameworks that will improve the lives of older people in Wales.

[91] Collectively, Age Alliance Wales member organisations possess extensive experience of service development and service delivery knowledge in a range of policy areas. All organisations also act at a strategic level as well as an operational level, and many of our organisations are member based.

[92] We had to make a conservative estimate as to our reach, because one or two of our organisations have a reach of over 6,000 and one or two have a reach of a few hundred. The reach of Age Alliance Wales is well over 100,000 older people in Wales. So, we come to you this morning with back-up.

[93] You have already heard from many of our members, so we have tried to co-ordinate that response. We have three key asks as Age Alliance Wales, which we have brought to the Assembly before, and we have gathered the evidence into these three key asks to try to make it coherent.

[94] One ask is that older people and carers have access to early intervention and preventative care services to help maintain their health and wellbeing when older and when growing old. Part of our drive in this work would be to work with those approaching older age and the need of services, to give them a much better perception of the potential of a residential care setting. We all know that an awful lot of negative stories in the media have, quite rightly, exposed poor practice. However, we would look to draw on and highlight good practice, because the negative stories have created fear among an awful lot of older people.

[95] Our first ask also includes housing; you will hear evidence from housing representatives. Maintaining housing to delay admission to residential care is one example. It also includes the disabled facilities grants, and we are delighted that the Welsh Government has backed the rapid response adaptations programme through Care and Repair.

[96] There are issues around people entering residential care. There is a lack of adequate

support in the community to meet specialist needs, particularly in relation to sensory loss and other specialist areas. Rapid identification of need and the provision of adequate reablement and long-term support could reduce the need for residential care. Age Cymru representatives from Swansea bay note that there are good alternatives to residential care, such as sheltered housing and extra housing care, which you have already heard about today, but that a lack of awareness and availability in the area can mean that professionals often suggest a residential care setting rather than look at other options. Older people should be enabled to make more informed decisions through the use of independent advocates and, where possible, be able to visit residential and alternative care settings to speak with current residents and service users before making their decision.

[97] Our second ask is on learning, training and the need to develop skills to support their wellbeing. At this point, I will refer to Rachel and a document that is available on the National Institute of Advanced Studies website, which is one of our members, on enhancing informal adult learning for older people in residential settings. Rachel has one or two key points that she would like to raise, because it is often an area that we do not bring into our thinking about residential settings.

[98] **Ms Lewis:** I will kick off by saying that a key point is that, in research conducted by the Alzheimer's Society, 54% of people said that their relative in a residential care home did not have enough to do during the day. The NIACE report looks at how activities for older people can lead to a range of benefits, which are all listed, such as decreased incontinence, improvements in motor skills, a lower level of depression and less dependence on medication. Angela will refer to the person-centred plan, and we recommend that these activities be written in a person-centred plan, so that people are asked about their interests and what they would like to be doing during the day.

[99] The range of resources that NIACE has put together and made available in free downloads on the net includes guidance for the managers of care homes and the designated co-ordinators of activities. These downloads are quite handy to give ideas of what can be done. It has also produced a document called 'Inspirations', which includes 10 interesting case studies of good practice on learning in care homes. We want to flag that up as we think that it should form an important part of the inquiry.

[100] **Ms Roberts:** The final ask—and I am jumping ahead, but it is difficult to put 20 organisations' points into a succinct submission this morning—is that older people must have support, information and access to the reablement services they need to regain their independence, to feel included and have a sense of wellbeing and quality of life. It is estimated that at least a quarter of care home residents are stroke survivors and that approximately 11% of stroke patients are discharged from hospital wards directly into a residential setting. Critical among these factors is the absence of a recognised and agreed outcome measure to assess the quality of long-term care for stroke survivors. In addition, despite guidelines from the Royal College of Physicians, there is no requirement among care home staff to be trained to identify and/or meet specialist needs arising from stroke. The provision of clinical psychology services for stroke survivors is also a concern and, in that regard, Wales has scored consistently low in the past in RCP audits.

[101] A key yet often underestimated fact in stroke survivors' recovery is their psychological wellbeing—depression, a loss of identity, and a loss of confidence and self-esteem are common, and are a significantly debilitating side of stroke. There is an awful lot in the detailed paper that Stroke has submitted to us, but if you caught Radio Wales last night, you will have heard Anna talking a lot about those areas, and we are more than happy to answer further questions on that.

[102] Accessing external services and support is another frequently identified issue. There

is a lack of information, advice and advocacy available to people and their families during the process of choosing and entering residential care. The process is not clearly explained and, in many cases, there is a lack of support and assistance in making decisions about care options and choosing the right residential or nursing home.

[103] The most common type of inquiry to Age Cymru's information services relates to social care. Independent advice and advocacy services are essential in enabling people to make choices on the care and support services that are correct for them. These are patchy across Wales because of local funding. We would be looking for the Welsh Government to work with local authorities to ensure increased and consistent levels of funding for this high-quality independent advice. Care homes do not often access a wide range of external organisations that could support the residents, such as local visual impairment societies, Age Cymru, the University of the Third Age, Action on Hearing Loss, Help to Hear, Hear to Meet schemes and Sense. Such support could reduce isolation and help individuals to maximise their wellbeing. The wider issue is that residents would be much more a part of the communities in which they live. There is a feeling among residents and people preparing for residential care that it is a waiting room for God, instead of being a next phase in an active life. We would like to see that being moved forward.

[104] **Mark Drakeford:** We have very limited time left for this session, so thank you very much. We have had your written paper, which has given us a chance to look at those points in more detail. Given that we have only 20 minutes left for this particular session—although, as you said, we are hearing from many of your members individually at different points in this inquiry—I just appeal to Members to ask fairly short questions, and I ask you for fairly short answers, too.

[105] **Kirsty Williams:** You have described how the process of going into residential care should be managed: with lots of information, chances to visit the home and conversations, and I do not think that anyone would disagree with that. However, the reality, from the evidence that we have heard, is that most people go into residential care at a point of crisis, usually straight from hospital, and the individual is usually very frail and unwell and there is great pressure to get them out of the hospital bed, which is needed by someone else. What is your vision of how that process should be managed and how that can be achieved? Who should provide the independent advice on choosing care options, and who should pay for that?

[106] **Ms Roberts:** I will answer those in reverse order. On who should pay for it, that is a difficult question in these austere times, but working with the sector organisations is probably one of the better options. There is experience out there across a wide range of organisations providing specialist care, which we are here to represent today. I refer to my comment about preparing people who are approaching older age and possible need that they should have a much better range of information about care settings. We need to avoid knee-jerk discharges from hospital without information for family carers—and, with my carer's hat on, I have to say that they are often in a state of flux themselves over a crisis situation in a hospital, and so if a patient says 'yes' to something, the family just goes along with it. That gives them little time. I have heard from many families who have said that they were given no options or choices and were just told that the patient would be going to somewhere because it was the only place with a spare bed. Often, sadly, from the information that I have received, it is an inappropriate placement, without staff trained in specialist issues.

[107] **Kirsty Williams:** We are aware of the issue, but what is your solution? I am interested in your ideas on how we stop that from happening. How do we do that better?

[108] **Ms Roberts:** You do it better by ensuring that you have much better preparation, by working with older people's groups and groups of society generally. People need to know

what their options are and have the opportunity to make a choice early on. We will all probably have to plan for something like this—God willing that we get to that stage of our lives. We must seriously consider providing much better earlier information so that families can plan together so that, if and when something happens, they know their choice. Patient and person-centred care is about choice and control, and we must take bold steps to ensure that choice and control become bywords. It is difficult, Kirsty, and I think that hospitals are between a rock and a hard place, but if they have a better understanding of what is out there, and if there is enough information for our NHS colleagues, they will not feel rushed or pushed either. That would be a good idea. So, my solution would be better working between health and social care professionals and the third sector.

[109] **Darren Millar:** Thank you for your presentation. I wanted to explore something that you do not refer to a great deal in your paper, namely the role of carers. You just referred to it, in passing, in your answer to Kirsty. We have heard that supporting carers and improving support for carers could prevent people from needing to go into residential care. To what extent do you feel that there is sufficient or insufficient support for carers in Wales, and where do you think those improvements might need to be made?

10.15 a.m.

[110] **Ms Roberts:** That is my favourite topic and you want me to be brief. Oh, dear. [*Laughter.*] There is not sufficient support at the moment. As carers' organisations, we greatly welcome the Carers Strategies (Wales) Measure 2010, and we will be looking to try to monitor that and hold to account whether things have improved through the correct information being given at the first point of contact, which is often the NHS. The LE Wales research showed that the range of respite care services provided is not good in Wales. It is still patchy, particularly for specialist care. I refer here to parent carers and their situation, and older carers looking after older people who have specialist problems. It is quite poor, so you end up with people in inappropriate settings. We need to continue to support this unpaid, untrained workforce. My drive would be that we ensure that we have a decent training programme available to carers should they need it. To allow them to carry on, we need to ensure that they have the breaks that they need, and the emotional and psychological support to continue. Getting this right would be a sign in our society, if this group of people on whom we depend to support the NHS and social services could get proper recognition and could be included in all discussions and debates surrounding the person who has the care needs—as long as confidentiality were maintained. The Mental Health (Wales) Measure 2010 is another that will take things forward in many ways. However, there is still a road to travel on that.

[111] **Darren Millar:** Do you think that there ought to be a minimum entitlement to respite care?

[112] **Ms Roberts:** I have always asked for a minimum entitlement, but with the financial situation as it is, I have to be realistic. You get an allowance, but there should be a minimum entitlement to a break from your caring responsibility. To achieve that, we would need to look at the charging process and what carers need. However, given that they do it for nothing, I think that they deserve something back from the nation.

[113] **Darren Millar:** It is money well spent if it prevents residential care further down the line.

[114] **Ms Roberts:** Yes, money well spent indeed. Lack of support for carers leads to many breakdowns. I did some research in Powys many years ago looking at the health of carers. The cost of a breakdown to the NHS is enormous, because it means that two beds or two care settings have to be paid for. Very sadly, last week, in my own town, a gentleman committed suicide for want of care. Not good.

[115] **Mick Antoniwi:** The evidence that you have presented about the activity that is available to enable people to have an engaged and productive life seems to indicate that there is a serious failure to evaluate this properly within the regulatory system. Is that your view or do you have any comments on how that particular level of activity can be put far more at the forefront of the care system?

[116] **Ms Roberts:** There are many examples of good practice in Wales. That is why I would like us to concentrate on promoting them much more. There is an organisation that draws together activity organisers, which now has a link across Wales, and that helps to take a more co-ordinated approach. I think that you have heard from My Home Life and the work that it is doing. Sadly, to date, feedback that we have received across all our organisations indicates that reports from regulatory bodies are not sufficient to support choice on entry. Another piece of information that I have been given is that activities should not just mean bingo and line dancing—which are all great, but bingo for somebody who has dementia is a non-starter. An activity can simply mean standing or sitting by somebody, holding their hand, and getting interested in them as a person.

[117] **Ms Lewis:** I think that it is about seeing the person as part of the wider community, and encouraging schools and inter-generational groups to engage and work with them. There has been a push for more community-focused schooling, and residential care settings and sheltered homes have the opportunity to bring people in to do that. It could be cost-effective and we would like to see more recognition of that. Evidence from Age Cymru has shown that, when there is a reduction in activity, residents became more passive and interacted less socially. So, it is important to find ways in which we can all get involved.

[118] **Mick Antoniwi:** So, is it an issue of quality or of evaluation of quality?

[119] **Ms Lewis:** It is about quality of life and person-centred planning. What do people want? Bingo or knitting may not be what the residents in a care home want to do. So, they might stay in their chair and not engage with those activities. It is about putting the person in control. It all comes down to that, and to seeing activities as something that will extend their wellbeing as a person, and not as a tick-box exercise so that you can say, 'yes, we did bingo and knitting'. It is about seeing it all as part and parcel of the user experience.

[120] **Ms Roberts:** I take your point about quality, and I think that what you are asking is whether there should be something within regulation and inspection against which homes can be marked. The answer is: potentially, if it was done sensitively, but the whole thing is that it should be person centred, so it would be difficult to put it against a regulatory standard. However, I am quite sure that activity organisers across Wales would welcome the opportunity for a wider discussion.

[121] **Mark Drakeford:** I have a couple of questions arising from the written evidence that we have received. There is an interesting idea from some members of the alliance that inspectors' reports on residential care homes ought routinely to include feedback from residents, family members and so on, as part of what is reported on. We have heard evidence that residents of care homes are sometimes reluctant to make those sorts of comments, because of the power imbalance between them as a resident and the people who are running the home. Do you have any idea as to how we might be able to overcome that, because it seems to me that user feedback, as part of inspection reports, would be very useful? How can we do that in a way that would not make residents feel vulnerable, in seeing those sorts of views attributed to them while they are still residents?

[122] **Ms Roberts:** That is a major issue around advocacy in the care home setting, so that the residents feel confident to be able to say what they need to say. Some care settings have

family member support groups, while others do not engage at all: those are the two ends of the spectrum. I think it is about advocacy for the residents and support for the families involved. The issue we have in Wales is that many people are caring at a distance. Many of them are in employment and can rarely get to the home, and perhaps only at a weekend, when certain staff are not there and when there would certainly be no-one from the inspectorate available for them to talk to. We also need to take that into account.

[123] It is the only way, because I think that there is a generational issue here. When my generation get there, I intend to do as in the poem, and wear purple and rattle my stick against the railings. However, we have a generation in the residential care setting now who deeply respect people in authority. So, it is about enabling them. We do it through My Home Life: we engage residents by spending quite some time with them. You need to build trust, which is often difficult, and one of the things that hampers that in residential settings is when you have a huge turnover of staff so there is not that long-term relationship with the staff that enables residents to feel confident. However, feedback is essential, and there are various ways of doing it with a wide range of people. Regardless of whether they have sensory or speech impediments or mental incapacity, you can still get feedback. It takes time, and you need time with the residents to take that forward. I would welcome that, and I know that my alliance members would greatly welcome that, as a move forward.

[124] **Mark Drakeford:** In a piece of written evidence, I saw a suggestion that just as schools now must have schools councils, and GPs have patients panels and so on, there ought to be some expectation that residential care homes above a certain size have residents and families councils. 'Council' might be the wrong word, but the idea is that, as a routine part of what you would expect, you would have a collective forum, whereby residents and family members could come together to convey issues to the people running the home. Do you think that there is merit in that idea?

[125] **Ms Roberts:** There is. My concern is about over formalising this. Our constant thought is, 'do not create a tick box'. However, if it was in good practice guidance, and there was some clarity about the process so that it was not a case of realising, 'Goodness me, it is Friday', and having two members of staff rushing around getting everybody into a room and saying, 'This is the council; what are your feelings?' so that they can only respond, 'Huh? We do not know.' That is a great difficulty.

[126] The other difficulty that we can have arises when large companies that are not based in Wales buy up residential settings. Their policies and procedures are then driven by that external company. The manager in the home is, therefore, quite restricted. However, if you brought in guidance of that nature, I think that it would be very much welcomed.

[127] **Mark Drakeford:** We have a minute or two before we conclude, so are there any points that we have not had a chance to touch on in this brief session, or do you have any last thoughts that you want to leave us with this morning? If we have covered all of them, that is fine.

[128] **Ms Roberts:** The two key things that we want to leave you with are the public perception of care homes and the current fear of them in generations in Wales, and the recruitment and training of staff, especially around specialist needs. We have heard about stroke services, but Alzheimer's and dementia care, as well as neurological care, are also significant. We hope that more will be done. The Care Council for Wales does its best, but it is about implementation and the quality of staff that are employed. However, paid care work is perceived poorly among the public, and we need to alter that across Wales; it should be recognised and respected.

[129] **Mark Drakeford:** Thank you very much indeed. I will just mention, because it arose

in Angela's last piece of evidence, that, as Members will know, Four Seasons Health Care, which was the largest inheritor of Southern Cross care homes, has been taken over by the equity buy-up firm Terra Firma. As Chair of the committee, I have received a letter from Terra Firma offering to meet to talk about its plans. I have replied, inviting representatives to come to give evidence to the committee at our session in Wrexham, when we will be meeting providers of residential care in the private sector. We will see whether Terra Firma's offer extends to turning up to meet us there.

*Gohiriwyd y cyfarfod rhwng 10.27 a.m. a 10.41 a.m.
The meeting adjourned between 10.27 a.m. and 10.41 a.m.*

**Ymchwiliad i Ofal Preswyl i Bobl Hŷn—Tystiolaeth gan y Gymdeithas
Alzheimer's a Parkinson's UK Cymru
Inquiry into Residential Care for Older People—Evidence from the
Alzheimer's Society and Parkinson's UK Cymru**

[130] **Mark Drakeford:** Croeso ichi i gyd i'r Pwyllgor Iechyd a Gofal Cymdeithasol. Diolch yn fawr am ddod yma'r bore yma. Rydym yn derbyn tystiolaeth yn awr gan y Gymdeithas Alzheimer's a Parkinson's UK Cymru. Croeso i Sue Phelps, cyfarwyddwr dros dro Cymdeithas Alzheimer's yng Nghymru, Chris Quince, uwch swyddog polisi Cymdeithas Alzheimer's, Steve Ford, prif weithredwr Parkinson's UK Cymru ac, yn olaf, Val Baker, Parkinson's UK Cymru.

Mark Drakeford: Welcome, everyone, to the Health and Social Care Committee. Thank you for coming here this morning. We will now take evidence from the Alzheimer's Society and Parkinson's UK Cymru. I welcome Sue Phelps, acting director of the Alzheimer's Society in Wales, Chris Quince, senior policy officer for the society, Steve Ford, chief executive of Parkinson's UK Cymru, and, finally, Val Baker, also of Parkinson's UK Cymru.

[131] We only have three quarters of an hour for a session that will touch on some very important issues as far as our inquiry is concerned. I will therefore ask you for some very brief opening remarks before I turn to members of the committee for questions. Given that there are four of you, and I know that almost all members of the committee are likely to have some questions, I will not be able to allow all of you to answer every question. I will probably look to see who is best placed to make a response and ask the others to contribute only if there really is something additional that needs to be said. That way, we will get through as much material as we can in the time available. Sue, do you want to say something at the beginning, or is somebody else lined up?

[132] **Ms Phelps:** Good morning, everybody. I am very pleased to be here and to give you evidence for your inquiry. I work for the Alzheimer's Society and am currently acting director for Wales. The organisation is the leading charity for the care and support of people with dementia and their carers. We very much focus on information and support, particularly for those living in the community, but, obviously, when they move from the community into residential care or a hospital setting we are just as aware of their issues and needs, and we continue to provide support and advice. We are very strong in our campaigning for people with dementia and the issues around their care, and we focus on research as well. That is a very brief introduction.

[133] **Mr Ford:** Good morning, and thank you for giving Parkinson's UK the opportunity to present evidence on this really important issue. There are 127,000 people in the United Kingdom living with Parkinson's, with about 6,000 in Wales. It is a condition that predominantly affects older people, but one in 20 people with Parkinson's are diagnosed before their fortieth birthday, so this is not just an old-age issue. There are some real challenges in living with a condition that impacts on movement, predominantly, but also on

all aspects of life. There are what we call the non-motor symptoms, which can be speech problems, depression, dementia, constipation, and a whole range of challenges. We are here as a charity to make sure that people get information and support, to raise awareness of the condition, and to provide a whole range of support mechanisms and training to help health and social care professionals provide better support to people living with Parkinson's.

[134] **Mark Drakeford:** I will go straight to Members now, who will have questions on the written evidence, which we have had a chance to read.

10.45 a.m.

[135] **Darren Millar:** Thank you for your papers. I wanted to ask a question about dementia. Your paper has a section on the process by which people with dementia enter residential care, and you have some remarkable statistics. One suggests that people with dementia who have a carer are 20 times less likely to end up in residential care. Another statistic is about the fact that around half of people who remain in hospital unnecessarily are people with dementia. On the first point, in terms of people with appropriate carers and care support, do you think that sufficient support is being given to those who live with someone who has been diagnosed with dementia to allow them to support their loved one in their own home?

[136] **Mr Quince:** At the moment, unfortunately, we know that many carers do not have enough support. We conducted a report in 2011, which covered England, Wales and Northern Ireland, which found that over half of carers did not get enough support to enable them to carry out their caring role. So, absolutely, there needs to be a development of services for carers of people with dementia.

[137] **Darren Millar:** What sort of support are you talking about?

[138] **Mr Quince:** I am talking about a range of support including respite care, which could benefit some people, peer support networks and those kinds of services, as well as domiciliary care to enable the person in the home to continue to carry out that caring role and to get the support to continue to do that.

[139] **Darren Millar:** Some of the witnesses that we have received evidence from have suggested that there ought to be a minimum entitlement to respite care. Is that something that you would acknowledge and support?

[140] **Mr Quince:** Absolutely; there needs to be a development of respite services, and more people need access to respite.

[141] **Darren Millar:** To touch on the issue of 50% of people who are in hospital unnecessarily being people with dementia, is the reason that there is a delayed discharge because there is a shortage of service provision out there in the community or is it because people need access to EMI residential care and they are not able to be discharged into that because there is insufficient capacity in the system? What is the reason for 50% of people who are in hospital unnecessarily being people with dementia?

[142] **Mr Quince:** There is a range of reasons: it could be a lack of access to social services, a lack of support for the carer or issues with the hospital in terms of supporting the person in the hospital. There are a lot reasons to do with discharge and it is probably a mixture of all of them.

[143] **Darren Millar:** I want to focus on the issue of EMI provision in residential care. It has been suggested to us that there is an insufficient number of EMI beds in residential care

across Wales and that that is something that has developed over a period of time and needs to be addressed. Some witnesses have said that there needs to be an abolition of that categorisation of EMI care within the residential care home sector and that all homes ought to be able to cope with people with dementia because it is so prevalent these days. Is that something that you think would be a good idea?

[144] **Ms Phelps:** I, personally, would support that idea as dementia is such a growing problem. We know that two thirds of the people living in residential care homes in Wales and across the UK will have a form of dementia, so that is the majority of the people who are living in care homes. If we are going to upskill staff, which is what we should be doing to care for those people's needs, why not train them fully in understanding dementia and raise their awareness of dementia and the condition? There will then not be any barrier to anyone going into a residential care setting.

[145] **Darren Millar:** Do you have examples of individuals who started off in general registered residential care homes who then had to move to EMI homes as a result and how unsettling that can be for people?

[146] **Ms Phelps:** There are certainly many examples of older people where the difficulties with their care have meant that they have been moved into a nursing environment—that could be in an EMI nursing home or it could mean going back into hospital. Also, as Steve mentioned in terms of people with Parkinson's disease, Alzheimer's disease and dementia affect many people under the age of 65. Dementia progresses much more rapidly in the younger person. If someone manages to get a place in a care setting, that is an achievement, because there is no appropriate care for the younger person. If they are in a residential care setting, very often, when their condition progresses to a certain extent, the only way that they can be managed is in a nursing care environment or by being admitted onto a hospital ward.

[147] **Kirsty Williams:** Obviously, the ideal situation is for people to be able to remain in their own homes in their communities for as long as possible. To what extent can community-based care services provide for the needs of people with conditions such as Parkinson's and Alzheimer's in their own homes? It seems that, in the past, there has been a stark choice for families: people are either told to manage at home or they hear the dreaded sentence that they need to put their wife or husband into a home, and there is obviously huge resistance to doing that. We are beginning to see some extra care housing schemes that allow couples and families to move in together so that the person who is unwell and the carer can move into an apartment together and those services are on hand to support them in their caring role. Do you think that there will be a growing demand for that sort of option so that families, husbands, wives and couples are not separated and also so that the person who is well has some confidence that, should something happen to them, their relatives are already in a setting that will be able to continue to care for them, at least in the short term?

[148] **Mr Ford:** Val, you have a lot of personal experience. Perhaps you would like to reflect on some of that.

[149] **Ms Baker:** I do not work for either of these societies—I have been on the receiving end—and that is why I am so nervous. My father had Alzheimer's and my mother has Parkinson's disease. We kept both of them at home for a very long time. It is a big story and I am not quite sure where to start. What you are describing is a wonderful idea because to move your spouse into a home when you just cannot cope any more is so sad and traumatic. Also, because people are living longer, this stage of extra life is not going to be a healthy life when we can all work longer; it may be a time when a lot of people will be very ill. We have to provide quality care in that time. I have very wise friends my age who are downsizing off their own bat. That is so sensible because if you can downsize, it is not so traumatic and, if you have support behind you, you will be ready for whatever may or may not happen. Often it

is too late, when you suddenly find that dementia has struck, because you no longer have the faculties to prepare for your own future.

[150] If I may quickly come back on something else that was said, I go along entirely with the idea that everyone should be able to move into residential care. However, I would like to flag up one thing, which is that there are care homes that have a dual role. If the person with dementia is of the very verbal type—they may be whining and screaming—they can be moved out of the hearing of those who do not have dementia because that is so upsetting. I could talk about this for hours.

[151] **Kirsty Williams:** I am thinking about the extent to which we can realistically provide services within the home. Are we set up to do that?

[152] **Ms Baker:** I had direct payments, which were a godsend. My parents' savings dropped and we easily spent more than £100,000 on care, but the direct payments clicked in just in time. There are disadvantages to direct payments because, sometimes, the system is complicated. People talk about having to become an employer. I did not want to take on those responsibilities; I did not feel qualified to do so. However, I used that money to go to a caring agency, so I did not have any of the health and safety issues to deal with. It was so straightforward, it was absolutely wonderful. For many years, we had a live-in carer and I would have carers coming in from other agencies. I could choose when I wanted them to come. They had to come at the appropriate times; they did not say, 'We can only come here or there'. That was a wonderful thing for me.

[153] **Mr Ford:** For me, it is about having a system that is oriented around keeping people at home, and that being seen as the priority and the default position. It is about ensuring that people are given the information and support to help them to understand what is possible. Val talks about some great support in terms of home adaptations and all of those sorts of things. It is about having good access to specialist care as well. Parkinson's UK really champions Parkinson's nurses because, with the whole range of symptoms of Parkinson's, you need someone who can really help families to focus on what the trigger points could be and prevent them so that people can stay at home. All of those elements are really important to keep people in their homes, which is what we all want to be able to do.

[154] **Ms Phelps:** I absolutely endorse what you are saying. The ideal place for someone with dementia is their own home. If someone is confused, they need a secure and safe environment that they are familiar with. Extra care facilities where family members and spouses can live with the person with dementia are fantastic. We are currently doing some work in partnership with Gwalia housing association on a project for Gorseinon in Swansea to put up an integrated care facility there. The idea, once it has been through planning, is to have extra care facilities—small bungalow settings—for people with dementia, but with 24-hour nursing care on site. It is next door to NHS day hospital support provision. If that comes off as we hope it will, that will be a model of good practice from which we can learn.

[155] I also think that the integration of residential care homes into the community could be better, so that older people in the community and older people in the early stages of dementia start to visit their local residential care home, are familiar with the staff and surroundings and vice versa—people living in residential care homes should be able to access all the services out in the community. For example, the Alzheimer's Society provides dementia cafes out in the community; in Newport and other parts of Wales, we have people from residential care homes with paid carers coming and joining us in dementia cafes, integrating with people who are still living in their own homes in the community. It works really well, and there is no reason why we cannot have more of that. If, as the Welsh Government is saying, we are going to work towards the ambition of dementia-supportive or friendly communities in Wales, that sort of service can promote independence and wellbeing, reduce isolation and do all those

things that can empower and enable people to live in their own homes for as long as possible.

[156] **William Graham:** To go back a little to assessments of need, both of you make play of this. Parkinson's UK Cymru says,

[157] 'Assessments should explore ways to ensure independence and avoid unnecessary admission to residential care'.

[158] The Alzheimer's Society says that specialist assessments need to be developed,

[159] 'which are systematic and standardised in approach.'

[160] I have no argument with either of those statements, but how can they practically be achieved, because, usually, admission is at a crisis point?

[161] **Ms Phelps:** Yes, it is usually at a crisis point. Going a step backwards, in terms of people with dementia and a diagnosis, we have very low rates of diagnosis, so only a third of people who are admitted into residential care will have a diagnosis of dementia. That is found out once they are there, and then the staff and the set-up are not geared up for that person's needs. Diagnosis at the outset is crucial so that if that person is admitted into hospital care or residential care, their needs and diagnosis are known, as is whether they are using medication.

[162] **Mr Ford:** People who go into hospital who have Parkinson's are well known to the system beforehand. It is about integrated care and health records, ensuring that as much information is available as possible, and forward planning. It is almost inevitable that those crisis situations will arise, so it seems that there is a responsibility on the system to be forward thinking and to plan and understand those dynamics, so that those options are built into the assessments and care planning.

[163] **Ms Phelps:** To back up what you said, Steve, as we all know, dementia is an age-prevalent illness, so the likelihood is that someone with dementia will be elderly. A crisis will not necessarily result from the dementia; it could be that the person falls and goes into hospital with a chest infection or a hip fracture. They are admitted to deal with that problem, so the nursing staff concentrate on it and do not see the person holistically. Someone with dementia can become very distressed and disorientated in the hospital setting. They may become undernourished because they are not able to feed themselves and there are all those sorts of things that we know about from the Commissioner for Older People in Wales's report on dignity of care on hospital wards. So, those things make it difficult to discharge that person; although they could have been discharged once the hip was healed or the chest infection was treated, their dementia may have progressed to such an extent that it delays their transfer, whether it is to their home or to wherever else they may need to go.

[164] **William Graham:** So, you would agree that part of the solution must be better integration between the NHS and social services and that that is the key to ensuring as seamless a transfer as possible.

[165] **Ms Phelps:** Yes, and, as I said, it is about seeing the person holistically. They are not a condition, so they will have multiple issues, whether it is Parkinson's, Alzheimer's or a combination of the two plus a physical problem—that person may have cancer. It is not about seeing the condition, but the person.

11.00 a.m.

[166] **Mr Quince:** Just very briefly on the issue of diagnosis, it is absolutely crucial that diagnoses happen and that they happen early. Unfortunately, we know that Wales has the

lowest diagnosis rate of any country in the UK. So, increasing the diagnosis rate would allow for support in the community and services. We know that implementing services in the community can reduce the need for residential care: people can be cared for for longer, and they may have more options, such as going into extra care and other opportunities.

[167] **Mr Ford:** With Parkinson's disease, it is really helpful to get the medicine to people that helps them to stay mobile—we have a 'Get it on time' campaign, which says that people should have the drugs at exactly the right time. What often happens, however, is that people with Parkinson's disease are admitted because they have fallen, or they have a chest or urine infection, and, as Sue was saying, people then treat that aspect of the condition and not the Parkinson's, so that patients often do not have their drugs, or they are given out when the drug round happens. People really deteriorate as a consequence of that, and that often precipitates the need for residential care or whatever.

[168] A trust in Scotland that I was talking to yesterday has a mechanism whereby it has a register of people who have Parkinson's disease. When someone on that register is admitted to A&E, the specialist nurse gets an e-mail through the interface between databases to say that that person is on ward 6, and that nurse will then go to ward 6 and really make sure that the staff there understand the medication issues and the Parkinson's issues. That means that the recovery from a fall or a routine operation can be so much better and people are more likely to be able to return to their homes. It is that kind of planning that makes a real difference.

[169] **Mark Drakeford:** I am going to go to Elin next, but before that, I have two separate questions arising directly from the last question. The first is just for me to check that I understand correctly what you are telling us. We have had quite a lot of evidence of circumstances in which someone is reasonably well and managing, and then something happens to that person that is a crisis. You can see how it is quite difficult to plan in those circumstances, and inappropriate admissions to residential care sometimes follow. However, both of the conditions that we are talking about in this session are established and progressive. Are you saying to us that, even in those circumstances, when anybody who knows much about it can see that a point will come when someone will need more help than they are currently getting, residential care becomes an option mostly in a crisis rather than in any thought-through and future planning sort of way?

[170] **Mr Quince:** Unfortunately, that happens very frequently with dementia. The system of eligibility for access to services—the fair access to care services criteria—means that there are not the services available in the early stages for people in their own homes. Those services are only available when a condition has reached the advanced and critical stage, which means that the support is not actually available. Services such as ours can be really beneficial, but domiciliary care and specialist services of that kind are just not there to access, so people do hit a crisis, and the diagnosis rate contributes to that.

[171] **Mark Drakeford:** Is it a similar picture with Parkinson's?

[172] **Mr Ford:** Sorry; explain the question again. It is obviously a progressive condition.

[173] **Mark Drakeford:** Parkinson's is a progressive condition and you might be able to predict that a point will come when someone will need more help than they are getting at the moment. So, a potential admission to residential care, one might think, would be something you could plan for, because you can see the time coming when it will be needed. Are you saying that, even in conditions where it might be possible to predict in that way, actual admissions happen in a crisis rather than in a planned way?

[174] **Mr Ford:** Yes, I think that that is right. You know that there is a progression, but you cannot predict the rate of it or what the trigger points will be. You do not know when

somebody is going to have a fall or contract a urinary tract infection. They are often the triggers here.

[175] **Ms Baker:** I would just add that you fight against it, because you do not want that to happen. It is only when something like a fall happens that other people will intervene.

[176] **Mark Drakeford:** I see your point.

[177] **Ms Phelps:** Also, a crisis might not necessarily be due to something like a fall. Even where a carer is involved, you cannot plan for when that carer's stress levels reach such a point that they can no longer care for someone. It is very often then that a crisis occurs.

[178] **Mark Drakeford:** Thank you; that is very helpful. My second question is related to that point, but is slightly different. We have heard quite a lot of evidence about people whose residential care is going to be paid for by the public purse. There is at least a system there, because the local authority has a direct interest in these decisions, which, when it works well, reviews all of the different options available to that person and means that that person ends up in residential care only when that is the right option, rather than because it just happens to be the path that is easiest to follow. However, we have also heard evidence that, for self-funders, the level of advice available to people making that decision is a lot more sporadic and less organised. It can be a matter of chance, really, whether someone gets the advice they need about the range of possibilities that might still be possible for them. Is that your experience? Is there a difference in the system between self-funders on the one hand and publicly funded care on the other?

[179] **Mr Ford:** There is an issue about the availability of information for everyone, but certainly we have had a lot of feedback from self-funders that it is a real challenge. It is a challenge to care for people who are living with Parkinson's. As a charity, we invest a lot in local education and training teams that deliver programmes within care homes to help people to understand medication, the fluctuating nature of the condition and the range of different symptoms. People who have Parkinson's would really like to know which care homes have made use of that education, have built it into their ongoing programmes and have a focus on Parkinson's, so that people have confidence that the homes will have some understanding of the issues. However, there is no way, really, for people to get hold of that information. They can ask us, I guess, but most people do not do so, because they are not routinely told that we are here and that we can provide that service. So, there is a real challenge with regard to how the system collectively can ensure that people can make those choices on the basis of which of the homes in the local area focus on Parkinson's and have had training on Parkinson's. That can make a real difference.

[180] **Ms Baker:** We were self-funding and I certainly had no information. I was given a sheet of paper with a list of homes, many of which had no places anyway. I tried to look at inspection reports on the internet, but I did not pick up a lot of what I was looking for regarding whether certain homes had expertise in this area or knew about a Parkinson's specialist nurse, for example.

[181] **Mark Drakeford:** Thank you; that is very interesting.

[182] **Kirsty Williams:** Having gone through that process and found it to be inadequate, what kind of information would have been useful for you when making those decisions? We might have an idea of what would be useful, but that could be completely irrelevant if you are going through that process.

[183] **Ms Baker:** It would have been of great value for me to know that a certain home had, perhaps, other patients with Parkinson's or had input from a specialist Parkinson's nurse, or at

least had staff who had some experience of it. A quick example is that I was told that my mother was being rather stubborn because she would not move her arm, whereas I thought that it was due to the rigidity caused by Parkinson's. She seemed to be asleep a lot of the time and it did not seem to be a natural sleep. When I was able to get a specialist Parkinson's nurse in, she said that my mum was comatose and needed certain medication at certain times. The home was very willing to take all of this on board, but it was as if they had never heard of this before.

[184] **Mr Ford:** That is a very good example.

[185] **Ms Phelps:** I think that, possibly, such information could be given during the carer's assessment. It is my understanding, from talking to carers, that they are assessed on what they need at that moment in time to enable them to support the carer at home. If they were given the information and there was a bit of forward planning and forward thinking about what is available should the carer need it, that would be reassuring. If someone knows that there is something there should they need it, it can enable them to cope for longer. It also means that, should that crisis arise, they know, in our case, where there are local homes where staff are trained to cater for the needs of people with dementia.

[186] **Lindsay Whittle:** The continuum of care is extremely important, is it not? Sadly, both of these illnesses are degenerative. What can the Welsh Government do to help your voluntary organisations train the carers who work in residential homes? With respect, from the evidence we have heard today, there does not seem to be much out there. How can we get this information out there? Can you give us any advice or help on how we can get this information out there?

[187] **Ms Baker:** It is almost as though they need a directive to say that there are tremendous resources available. I have had so much support and help from these societies. Carers are willing—they are unsung heroes—to take it on board, although they are under so much pressure with their jobs. However, if you are not aware of an area of knowledge, you do not go searching for it, but it is there.

[188] **Mr Ford:** For me, it starts at the beginning. We have just done a survey that shows that, when neurologists give a diagnosis of Parkinson's, less than 50% signpost people to the fact that Parkinson's UK exists. We have a network of information support workers, helplines, a website and a whole range of accredited information resources, so it is fundamental that all NHS and social care guidance, frameworks and performance management regimes include a bit about working with the third sector. It is bizarre that we provide all the support but that we also have to provide lots of support for marketing our services to care homes, consultants and everyone else. You would think that people would be knocking our door down, but they are not. There is an issue here about the mentality of our services that does not see the third sector as natural, willing partners in all of this.

[189] **Lindsay Whittle:** Should it be part of the inspection regime?

[190] **Mr Ford:** It clearly should be, because if people are not well connected, their residents are not accessing a tremendous amount of support that is available.

[191] **Ms Phelps:** I would fully endorse what Val said about making it mandatory. As far as dementia is concerned, going back to what I was saying, a third of people in residential care homes will have dementia. Mandatory dementia awareness training should be relatively easy to do. As an organisation, we provide training. We are asked for it, and there is a growing demand for us to go in to do that type of awareness work. I have been to training events with extra care staff, for example, where they have been very reluctant at the beginning of the two-day session—you can almost see that they have been dragged there—but by the end of the

two days they all say, ‘Gosh, if we had known this when we first started, it would have made our lives so much easier’. It helps if they know why a person is behaving in the way they are and that there are ways of communicating with someone with dementia—even though they might not be able to verbalise it. They can then get to the bottom of what is making a person behave in a certain way—it could be pain, distress or loneliness because no-one is speaking to them. There can be lots of reasons why a person is presenting with aggressive or agitated behaviour, but it is often treated with medication inappropriately, because it is easier. Having the time and understanding can tick many boxes. So, staff have been really grateful for the awareness raising training, which is relatively easy to do.

[192] **Mr Ford:** People are really vulnerable in these settings. As Val said, it was thought that her mother was being awkward or stubborn. With Parkinson’s, you struggle to make facial expressions, so smiling and engaging in that way is quite difficult. These are incredibly vulnerable people and, without that understanding, they will be labelled as being awkward and unfriendly, which opens up the risk of being abused in some significant ways.

[193] **Ms Baker:** Many of our carers are very young, and it is difficult for them to understand that old people were once young. It is as though they have a label of ‘old and going nowhere’. It reminds me of when I was in school, years ago, when we were not so aware of special needs, how many there were and what you could do to address them. Old people seem to be lumped together with this one label. As another example, there was a tremendous uproar in the Royal Gwent Hospital years ago because my father, who had Alzheimer’s, was said to be ‘performing’. When I went in to investigate, he was not being co-operative when they wanted him to get into bed, and I said ‘Yes, but from his perspective, you are coming up and taking his clothes off him, so how do you expect him to react?’ That says it all, really.

[194] **Mark Drakeford:** Mick has an extra point on this, and then we will go to Elin, I promise.

[195] **Mick Antoniw:** Parkinson’s UK’s evidence says that

[196] ‘despite regulation and assessment of services, there remain concerns over the quality’

[197] and so on. In terms of the regulatory regime, there seems to be a criticism or a highlighting of failure of the regulatory regime. Is that correct, and what specifically would you like to see changed within the regulatory system?

11.15 a.m.

[198] **Mr Ford:** I do not think that I can present lots of evidence to you about this, other than the stuff that comes up in the general media. I suppose that it is just a matter of recognising that this is an environment in which you often have quite junior, low-paid staff working with people who are in vulnerable situations without a great amount of supervision. Therefore, to some extent, it is not just about inspection and regulation, although that is an important mechanism that needs to be as strong as it possibly can. That is all we are saying here.

[199] **Mick Antoniw:** It needs to be addressed.

[200] **Mr Ford:** Yes.

[201] **Mr Quince:** There is an ongoing issue with regulation and care standards. How you stop things like abuse happening and how you improve quality are not currently addressed by

the regulations. They are a reasonable set of regulations, but given that two thirds of people in care homes have a form of dementia, we absolutely believe that there needs to be more reference to dementia in those regulations and more reference to training and strong enforcement, so that where there are breaches, regulators have to go in and respond to that breach.

[202] **Elin Jones:** In my area, Ceredigion, a most distressing situation that families have found themselves in is that of the assessment of someone in residential care who has dementia changing suddenly and that person then requiring a different setting, such as an elderly mentally infirm residential home or an EMI nursing home, but in a rural area, and possibly in other areas, those homes may be miles and miles away. In Aberystwyth, for example, there is no EMI nursing home and you need to travel about 50 miles to the nearest one. That is incredibly distressing, not just for the individual, but for the family support network, too. Do you have any views at all on how flexible the system could be to allow people who have dementia who have increased needs to move more seamlessly and less traumatically? The same may also be true of Parkinson's. The system has a specific way that people should be cared for, and the individuals seem to get lost in the system rather than staff thinking about what is of benefit to the individuals and their families.

[203] **Mr Quince:** It is complicated. Obviously, it is very distressing when people have to move a long distance, but, equally, you do not want people in inappropriate care settings. We know that moving people who have dementia from care homes can be incredibly distressing, depending on the stage they have reached. It is about ensuring that all homes can cater for people with dementia and that that is core business. There is also a need to develop care settings that have different components and needs met on the same site—extra care with residential care and a nursing home all on the same settlement, for example—so that people can move up when they have different needs but remain in the same environment. Those kinds of options could be really beneficial, especially in rural areas.

[204] **Kirsty Williams:** That is particularly challenging to deliver in a rural area because you have a relatively small population. So, you could not have one of those settings in Aberystwyth, one in Aberaeron and one in Rhayader, for example, as the finances do not stack up, do they?

[205] **Mr Quince:** Absolutely.

[206] **Ms Phelps:** What I think we are talking about is a person moving from residential care into hospital and perhaps back into residential care and then into a nursing home. Why can we not think about that person going back home at some stage? Once a person has been assessed, and their condition has progressed, if they are properly assessed and provided the proper care packages are in place—so that, if there has been a carer breakdown, the carer has had a break and an appropriate respite to enable them to recharge their batteries—that person could go into residential care, be assessed, have their condition settled and hopefully be able to go back home. However, given the bureaucracy involved, the paperwork, the assessment process, and the interaction between community mental health teams, local authorities and health staff, once a person is in a particular situation, it is easier to keep them there than it is to think about possibly moving them back. So, it is about changing the mindset and thinking about what is right for the person. I have no doubt that it can be done, but all agencies need to work together, including the third sector, to enable movement from one care environment to another, including the person's home.

[207] **Mark Drakeford:** Professor John Bolton in his evidence to us said that around a quarter of people who are in 'nursing' care do not need to be there, that their condition will have recovered enough, in the way that you described, for them to be de-escalated in the system and for them to be moved back into, for example, a residential care home. However,

he said two things. The first was that the system does not think about things in that way because it is a one-way street in which your needs are always getting greater. However, the other point he made, which was slightly different and also similar to the point that Chris was making, is that people do not get moved back because, by the time someone has recovered enough to do so, they have become familiar with the nursing home they are in. They know the staff and the place. We also know what mortality implications there are for people being moved around the system in that way. So, a person is not just left there because the system has forgotten about them or is rigid, but because people think that it would be bad for them to have another move. So, they stay in a nursing home, getting a level of care that they do not actually need because people are anxious about the effects of another move on them. Does that ring true with you?

[208] **Ms Phelps:** Yes, I cannot argue with that. If a person is settled and comfortable, safe and secure in a certain environment, then there is no reason to move them. It would be more distressing if they were moved.

[209] **Ms Baker:** There could also be a change in someone's mindset, because that is what happened to my mum, all because of a pressure sore. She is a different person now to a year ago. Although she is in a wonderful home, and I will not criticise it, just the fact of being in a home has so demoralised and depressed her that she is not the person she was, and it all seems a bit pointless to make this move.

[210] **Ms Phelps:** On training in the residential care home setting and on using the third sector and organisations such as ours as points of reference and being able to provide the expertise, this is not just about the third sector because we should make much better use of carers. Some carers have been caring for a number of years, and we, as an organisation, provide information programmes to enable them to care, to raise their awareness of the condition and how they should look after themselves and so on. If a person with dementia then moves into residential care, why not use the expertise of that person's carer? Resources are tight, so the staff in the residential care home could use the family member, the carer, to help them to up-skill and raise the awareness of their staff.

[211] **Mark Drakeford:** I want to ask a question related to Elin's point on language. I am particularly interested in language in the Alzheimer's context. With someone whose mother tongue or first language may not be English, as the condition develops, does that become a more pressing issue for people and, if so, in a Welsh context, does that throw up particular challenges of being able to provide care for people through the medium of Welsh?

[212] **Ms Phelps:** Definitely. You are absolutely right. A Welsh-speaking person with dementia might have used English for the majority of their life but they can revert to Welsh once they go into the later stages of their dementia. We have to accept that there are very few staff, certainly within our own organisation, who can provide support in the Welsh language. That is an issue and we need to tackle that much better.

[213] We produce a publication called, 'This is Me', which is used in the NHS. We have sent it around the local health boards in Wales. We want it to be used not just in hospitals, but also in residential care settings. That document is now bilingual. It is a basic A4 document that details a person's likes and dislikes, what they prefer to be called, their name, as well as lots of details about their family history. That was originally provided only in English and, of course, some of the local health boards, such as Betsi Cadwaladr, said that they would not use it because it was not in the Welsh language. So, it is now produced bilingually and people can complete that information in Welsh and say whether they would prefer to communicate in Welsh, but it is a big gap.

[214] **Rebecca Evans:** What is your assessment of the range, quality and appropriateness of

the activities people are able to do in residential care settings, particularly for the groups of people you represent?

[215] **Ms Baker:** My experience of a number of homes is that they are quite standardised. You get bingo, line dancing, a hairdresser comes in, and you make an Easter bonnet at Easter. That may be perfectly fine for many people, but it is not for everybody, either because their cultural backgrounds are different or because of their dementia, so they have no means to access and enjoy that sort of thing. I also feel that much of it is entertainment, and that, wonderful as entertainment can be, I find that mum needs a purpose for living and needs to feel valued, which is difficult when you cannot do anything. I tell her that it is important that she is there and that she is still in charge and things like that. However much you are entertained, if you are not actively involved or if you do not feel you have a value, it is almost irrelevant. Much more could be done. At the home where mum is now, they had a reminiscence session. It was so simple: they handed around things from the attic, such as a carpet beater. It was surprising how, slowly, those people came out of their shells. Very often, they are so used to being inactive that it takes a while to break through the barrier. There is great scope for a lot of improvement there.

[216] **Mr Quince:** With dementia, we know that there are not enough opportunities for social interaction and activities. Our 'Home from home' report in 2007 found exactly that, namely the need to have tailored activities that people can be involved in, such as reminiscence therapy or other services. Access to outside space is really beneficial so that people can do gardening or those kinds of activities, as well as involving people in activities such as cooking and preparing meals, which they will have done all their lives. Stopping people from doing them suddenly because they have gone into a care home seems incorrect, and enabling them to carry on cooking, gardening and those kinds of activities, as well as formalised reminiscence therapy and other services, can be beneficial to the individuals.

[217] **Ms Phelps:** One service that the society has trademarked is Singing for the Brain, which sets up singing groups out in the community for people who have dementia. In the Caerphilly local authority area, we have a well established Singing for the Brain group. The commissioners there have asked whether we could now do that in residential care homes. There was absolutely no reason why not, so we now have a facilitator and a contract to deliver Singing for the Brain in the residential setting, which is fantastic, because music can bring about so much change in a person's wellbeing and ability to communicate.

[218] **Rebecca Evans:** I have one final question. On the same topic, are there recommendations we could make to improve the kind of experiences people have of activities in care homes, whether to do with strengthening the guidance, providing extra guidance for activity co-ordinators, or including something in the person-centred planning on activities. How can we make this better?

[219] **Mr Quince:** My understanding is that the regulations will start looking at opportunities for social interaction and activities. That is beneficial and is a great first step. Including something on what local authorities or care co-ordinators can do to organise activities or putting reports on regulators' websites could also be beneficial.

[220] **Ms Phelps:** It is about changing the mindset and, as you say, encouraging person-centred practice within a care environment and outside the care home. I know of one extra care facility that has a garden that backs on to a comprehensive school. It works with the kids from the school, so the girls will do health and beauty and will come in and do the ladies' hair and nails. Some of the lads will come over and take the gentlemen over to watch a football or rugby match. They also do some life history work, where the kids go in and speak to the residents about the history of Cardiff or whatever. So, there are lots of things that can be done, but it is about raising awareness, as you say, and almost making it mandatory that this is

what you should be doing. It is an important part of a person's life. They are living within your—sorry, Val, you wanted to say something.

11.30 a.m.

[221] **Ms Baker:** [*Inaudible.*]—rather like schools, on what your place is within the community.

[222] **Ms Phelps:** I would also suggest that, if they are providing stimulating activities, care workers would benefit from that in terms of their roles, the feedback of the people whom they are caring for, and staff retention. It could make huge inroads.

[223] **Mr Ford:** We have support groups across Wales and the UK. Some care homes and nursing homes are good at encouraging their residents to attend those kind of sessions. That is the kind of thing that should be encouraged. So, it is not just about what is provided within the facility, but maintaining those connections with the wider community.

[224] **Mark Drakeford:** Thank you all very much indeed for what has been a very wide-ranging but interesting and useful session for us. Shortage of time has been a bit of a theme of the morning; we have run out of time in all our sessions today. So, I am sorry that there will not be a chance for you to sum up, but if you think that there are points that did not emerge as clearly or strongly as they might have done in this oral session and you would like to write to us to say, 'Don't forget this' and 'You really need to remember to take account of that', we would be very grateful for that. However, for the time being, thank you all very much indeed for your time this morning.

11.31 a.m.

**Papur Gwyn ar Roi Organau—Sesiwn Friffio Ddilynol gan Swyddogion
Llywodraeth Cymru
Organ Donation White Paper—Follow-up Briefing from Welsh
Government Officials**

[225] **Mark Drakeford:** I gently remind members of the committee that this is a briefing session. This is not a cross-examination session; we have officials before us, not Ministers, so they are not here to defend a policy. What we have asked them to do is come here to help to keep us in touch with what the Government is doing, so that when we come, as a committee, to carry out our responsibilities at Stage 1 of the Bill, we will be as up to speed as possible with what has happened.

[226] I have indicated to the people who will be helping us that there are three things we are particularly interested in. We will want to hear about how the consultation on the White Paper went. We will want to find out a little about it and we will be interested in hearing how the results of the consultation are being analysed. Most of all, we will be interested to learn how the White Paper stage of the process is feeding into what the Welsh Government plans to do next and to perhaps have an indication of what that plan is likely to be.

[227] Bore da a chroeso i Chris Jones, cyfarwyddwr meddygol gwasanaeth iechyd genedlaethol Cymru a dirprwy brif swyddog meddygol, ac i Grant Duncan, dirprwy gyfarwyddwr Cyfarwyddiaeth Feddygol Llywodraeth Cymru. Diolch i chi am ddod i'n helpu ni unwaith eto ar y Papur Gwyn ar	Good morning and welcome to Chris Jones, medical director of the national health service Wales and deputy chief medical officer, and to Grant Duncan, deputy director of the Welsh Government's Medical Directorate. Thank you for coming to help us once again on the White Paper on organ donation.
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roi organau.

[228] You have probably just heard me saying to Members as you were coming in that we are grateful to you for helping the committee to stay in touch with the work that the Welsh Government is doing on this topic so that, when we come to play our part in it, we will be as well informed as we can be. If you are happy to begin by updating us on what has happened since you were last here, there will then be questions and bits of extra information that I am sure committee members will want to ask about.

[229] **Dr Jones:** Thank you for inviting us back to provide a technical briefing. Since we were last here, we have completed the process of public consultation. We feel that we have been through a helpful and genuine process. We organised a number of public meetings, which we led. A relatively small number of people came to those public meetings, but the richness of the conversation, the range of views and the perceptive and intelligent comments made were helpful to us.

[230] We also arranged a number of other meetings with other stakeholders, partners and hard-to-reach groups in the community. Again, all of that helped us enormously. However, the real success of the public consultation was the huge number of responses we received—more than 1,200 responses, which I think makes it the largest consultation that has been run by the Welsh Government by some distance. We have learned a great deal from all of these responses to the questions that were asked of the public. So, we have been through a very helpful process, and we feel some reassurance as a result that we have confidence in a way forward.

[231] **Mark Drakeford:** Grant, do you want to add anything to that?

[232] **Dr Duncan:** One of the lessons I took from this was the ongoing communications challenge around the entire subject. In the public events, many people came with fixed views for or against, but the more we discussed the subject with them and were able to dispel myths and educate them about the existing system, the more people felt reassured in general. The need remains for good communication on the subject of organ donation as a whole, as well as on opt-out.

[233] **Lynne Neagle:** One of the concerns the committee had when you last came before us was that there did not seem to have been any specific attempts to consult with black and ethnic minority groups. Your paper says that you have tried to do that. Could you say a little more about exactly how you have engaged with that particular group?

[234] **Dr Duncan:** During the consultation, we sought to organise a joint meeting with various representative groups. Unfortunately, nobody turned up on that particular day. Subsequently, we have gone out and met the Muslim Council of Wales, the Faith Communities Forum and the Race Forum. We are open to any advice that anyone wants to give as to what more we can do in this regard. We are committed, throughout this process, to continually reach out to these groups in the best way possible.

[235] **Dr Jones:** I think that we have learned a lot from talking with different groups. When I went to the Race Forum, we learned a lot that will be helpful to us. For instance, a number of ethnic minorities did not realise that they are at much higher risk of requiring a transplant and are also demonstrating a low rate of registration, so they face a much longer wait and a higher risk while waiting. That was not apparent to them before, so I think that they felt that they needed to know that and that some sort of health promotion message in the communications would help to engage those communities.

[236] Colleagues have met representatives of the homeless; they have spoken to Shelter,

and we have received advice about that group. Clearly, it is difficult to communicate with homeless people. A number of people who are homeless will have only recently arrived in Wales, so a number of them will be excepted from this legislation. I know that colleagues have also met with Mind to talk about people with mental health issues and chaotic lifestyles. We have received some advice about the need to consider public places as a means of communication with those people and that they will often look for information in libraries and churches. Colleagues have also met Learning Disability Wales, and it has given us some feedback about the Mental Capacity Act 2005 and the requirement for fair treatment for those who may have uncertain mental capacity and the danger of assuming that they do not have capacity.

[237] Colleagues have also met the Muslim Council of Wales, which indicated that it is prepared to work with the policy and has encouraged us to ensure that we deal directly with local leaders, who may have a range of different views. Finally, I think that colleagues have met the Cardiff Gypsy and Traveller Project, which has helped us to understand that the word spreads through family links rather than individual representatives in that group. I understand that a lot of people in that group do not actually travel, but they are in different types of housing, and we can learn about where they are and how to get to them. So I think that there is quite a lot of understanding building up in this area.

[238] **Rebecca Evans:** Looking at the summary of responses you have had and the list of consultation responses, I see that a large number were responses with identical wording, circulated either by the Opt For Life campaign or the British Heart Foundation. How many of those pre-written responses did you get and how many original responses did you get? How did the numbers fall on either side of the argument?

[239] **Dr Jones:** I think that there were 485 Opt For Life letters. I do not know how many came from the British Heart Foundation. Those letters were standard letters, as you know, and we have been asked whether it is reasonable to regard those in the same way as any other response to a consultation. At the outset, we expected and committed to treating every response equally. It is true that it was a standard letter, but, on the other hand, we know that the Kidney Wales Foundation represents a large number of people who feel strongly about this issue. We came across them during the public consultation and, just because they may have benefited from a transplant or need a transplant, that in no way alters their ability to make their point and express a wish. So, we have included them along with all of the other consultation responses.

[240] **Rebecca Evans:** So, all consultation responses are weighted equally.

[241] **Dr Jones:** Yes. If I may pre-empt a question that flows out of that, namely whether it is then reasonable to say that 52% of the consultation responses represents a genuine majority, colleagues in the committee may be aware that, subsequent to the consultation, BBC Wales undertook a St David's Day poll of the population that showed that 63% of the population were in favour of this legislation.

[242] **Rebecca Evans:** I am also wondering whether the lack of clarity about the role of the family in these proposals has proved to be any kind of stumbling block to the consultation.

[243] **Dr Jones:** That may be right. We have encountered a range of different views about this. Some people will very clearly make the point that they would expect the individual's wish to be respected and that the family should have no say at all. Some people will say that very clearly. Others will make it clear that the family has an important role. That has been the feedback we have received from previous public consultation, and our commitment is that, although the rights of the individual are paramount, we need to approach the family and engage the family in conversations. We need to check the medical status of the person who

has died to ensure that they are suitable for organ donation and we also need to ascertain the known wishes of that individual at the time of their death. The family plays an important part in that. So, although there is no legal veto as such, and that has been a somewhat misleading term that some commentators keep using, we have made the commitment that, as now, no organs would be retrieved if the family vehemently objected. It would not appear to be in the family's interests or in the interests of the whole clinical situation or, indeed, of organ donation as a whole.

[244] **Rebecca Evans:** The question that flows from that, therefore, is how the proposed system would be materially different from the current system, if organs would not be taken without the family's consent.

[245] **Dr Jones:** That aspect would be the same. The difference is the confidence that a family will have about what an individual's wishes were at the time of their death. At present, clinical practice has moved on, so we are not reliant on the organ donor register. Through the Human Tissue Authority code of practice, we approach all families of a potentially suitable donor. In the majority of those cases, the deceased will not be on the organ donor register and, at present, about 60% of those families say 'yes', because they believe that that is what their loved one would have wished. However, 40% say 'no'. In the future, when there will have been an opportunity for someone to register an opt-out and there will be a much higher level of public awareness, so that people will have conversations around the dinner table about their wishes, we believe that a higher proportion of families will agree that this will be what their loved one wished. Indeed, that is the international experience. In countries that have systems of presumed consent or however it is termed, only about 5% to 10% of families will say 'no' and that is where the increase in organs becomes apparent. The number of people saying 'no' is down from 40% to about 5% to 10% because of the added assurance that they had an opportunity to opt out and did not take it.

11.45 a.m.

[246] **Kirsty Williams:** I wonder whether you can indicate what the ongoing timetable is for the legislation and whether you are planning to implement a communication strategy for the public that will run alongside the passage of any policy development. For instance, I have recently been contacted by constituents who want to know where they opt out now. I have to explain to them that we are a long way from having a system where they need to opt out. How will this progress? Are you planning a communication strategy for members of the public, who have very strong feelings on both sides of the argument, to communicate the passage of this particular policy?

[247] **Dr Duncan:** The broad timescale is to bring forward a draft Bill for consultation in June. A communication strategy will also be part of that and will be run in parallel. One of the messages we picked up from the public events was to do with communication. In broad terms, the message was: 'We believe you, Grant and Chris; you will communicate, but how do we keep those going over a longer period of time?' It is not just about the introduction of the Bill or passages beyond that period of time. A communication strategy will be brought forward alongside the Bill that will aim to talk about the existing system and the changeover. My team became well aware of the communication challenges around the last weekend before the consultation closed, when one daily newspaper's supplement ran an article that said 'last opportunity to opt out'. Our phones were ringing on the Monday. Generally, the calls were from older people saying, 'I'm concerned; how do I opt out now?' We are well alert to and concerned to get the communication strategies right, which is more than just about press notices. It is about using different channels. I do not tweet, so I am on uncomfortable ground here, but it using newer and appropriate channels for as many different walks of society as we can.

[248] **Dr Jones:** One thing that we learnt through the public consultation was that there is a remarkable lack of understanding of the processes that surround organ donation in general. It is not just the legislation. I do not think that many people will necessarily understand the legislation without understanding the mechanisms better. One fact that really seemed to surprise everybody was how few people can be organ donors when they die. We only have about 70 deceased donors each year in Wales out of over 30,000 deaths. I do not think that people realise that. They do not realise that you have to fulfil quite strict clinical criteria: you have to die under very controlled circumstances in a critical care unit and you cannot just be picked up off the street if you had an accident and have your organs taken. We had to explain a lot about the whole process in the public meetings and how there was separation of clinical care from decision making and actions relating to organ donation, which would not change. We realise that that is an important part of raising people's awareness in an informed way.

[249] **Mick Antoniw:** I am not clear whether you were any clearer as to what the timetable was going to be or whether that is currently beyond your knowledge. Do you have a clear idea of the timetable?

[250] **Dr Duncan:** A draft Bill will be brought forward in June of this year.

[251] **Mick Antoniw:** Sorry, I missed that point.

[252] **Dr Duncan:** There will be a further process of formal consultation and a formal Bill will be brought back later in the year. The anticipation would be that, if the legislation were passed, there would be an introductory period over two years, and you are then talking about up to 2015 or a longer changeover period.

[253] **Darren Millar:** I wonder about two things. One thing is the current thinking in terms of the retention of the register for the existing opt-in system. Obviously, if this legislation passes through the Assembly, there will be a register of those who have opted out. Then there will be a much smaller percentage of people in the general population who will not have expressed any specific wishes that are recorded on a list. However, it will obviously minimise the list if those two registers are maintained rather than there just being a list of those who have opted out. Can you add anything on the Government's current position on this?

[254] **Dr Jones:** I can say a certain amount. We made a commitment in the White Paper to retain the organ donor register, and that is because it is accepted and understood by the public and because it provides a means of actively expressing a wish to donate, which some see as an altruistic act. It also carries weight outside Welsh borders. Therefore, that commitment has been made. What we have learnt from the consultation about the issue of registering opt-outs is that, generally speaking, people felt that there should be a mechanism to register that. One could operate the system purely on the basis of conversations with the family and the family reporting the person's wishes, but the majority of respondents felt that there should be a system to register opt-outs and that that system should be as simple and clear as possible. I think that everyone emphasised the need to avoid confusion or conflict between different registers. I do not think that I can go into the exact form that a register or registers would take at the moment. We are still formulating policy prior to the draft Bill.

[255] **Darren Millar:** Obviously, the Driver and Vehicle Licensing Agency has played a significant part in promoting organ donation, with people opting into the current organ donation register through the renewal of driving licences and so on. However, one thing that has always struck me—I have not had any discussion about this, but it occurs to me to say it now—is that the passport application process might provide another opportunity for people to express a view on whether they want to opt in or out of organ donation in future. Has the Welsh Government had any discussions with the UK Passport Agency regarding the opportunity that might present for identifying people's wishes?

[256] **Dr Jones:** I am not aware of any specific discussions about passports. However, the Welsh Government has always been very keen to support all efforts made to increase registration on the organ donor register and, with my current Minister, I have attended activities in Cardiff and across Wales to encourage registration. Just this week, facebook has launched an initiative to improve registration, and we have been very supportive of that and registered our support on the Welsh Government facebook site and on twitter. However, the trouble we experience, despite all these different efforts is that the percentage of the population registered remains stubbornly fixed at around 30% to 32% or 33%.

[257] **Darren Millar:** I have one further question and that is on cross-border issues, which did not appear to feature too heavily in the consultation document. Did any respondents refer to cross-border issues and talk about the fact that people from England may die in Wales or that people who are usually resident in Wales may die over the border in England and whether they may have expressed a view on what they would like to happen when they die? What were the responses to that issue in the consultation?

[258] **Dr Duncan:** It came up in some of the public consultation events. Again, there was a mixture of views on that ranging from the view that, if you are in Wales, Welsh law should apply to the view that there should be a reasonable amount of time. However, I think that we were able to reassure people that it is their wishes that need to be followed through. It goes back to the question of how wishes are recorded and the fact that there needs to be clarity about that, as well as the fact that there are safeguards in place relating to the role of the family, because the family must be involved in decision making. That helped reassure people that it is not just an electronic system that records people's wishes, but that there is a system around it.

[259] Another question that came up in some of the events related to the cross-border use of organs. There were questions about where the organs of a Welsh donor would be used. We have consistently said that the system is administered by NHSBT on a UK basis and that that would remain the case. Subsequently, a minority of people asked, 'Does that mean that Wales would become an exporter of organs to the UK?', and very quickly, other loud voices in the audience said, 'Actually, that is not the case—we need to take a wider view than that, in terms of increasing the overall use of organs and the overall pool'. So, the cross-border issues came up, but not vociferously, if that is the right word—not in as anxious a way as we had anticipated they might.

[260] **Darren Millar:** In terms of hospitals that treat both Welsh and English residents, there may need to be arrangements within those hospitals to ensure that there is an approach that is consistent with the different legal jurisdictions in both countries pertaining to the residents.

[261] **Dr Duncan:** That is correct. The records will need to be open and transparent. NHSBT operates on an England and Wales basis and we are working closely with it in any case. One thing that I should have mentioned earlier is the role that the specialist nurses and clinical leads play in this; in today's system, never mind tomorrow's system, their role is absolutely phenomenal and they are the key in many ways to making this whole system a success in communication terms. We are working with them on their role, training needs and system needs.

[262] **Kirsty Williams:** Briefly, you said that people suitable for organ donation have to die in an intensive care unit; for many of my constituents, the nearest ICU is in an English hospital. We do not have any ICU beds in the county. Just to clarify, are you in discussions with health authorities across the border that would have services commissioned by the Welsh NHS so that they could operate the system for Welsh patients in a way that would potentially

be compliant with Welsh law and the wishes of Welsh patients?

[263] **Dr Jones:** We are not in discussion with health authorities, and I do not think that that would be appropriate now, because we are developing policy. The common link is through NHSBT. We have been very grateful to NHS Blood and Transplant for its support during this whole process; it has attended our expert advisory groups and some of our stakeholder groups, and has provided a specialist nurse for organ donation to clarify points of fact during our public consultation. As Grant says, it is an England and Wales body, and whatever comes out of the legislative proposals will be, to some extent, under the remit of NHSBT.

[264] **Mark Drakeford:** I have one last question to help us as a committee to understand the Welsh Government's approach to this. It would have been open to the Government to take a slightly more conventional route, which would have been to go directly from a White Paper to a Bill. However, the Government has decided to go through the additional process of having a draft Bill in between. Can you help to explain the thinking behind that? Why has the Government decided to have another round of that sort, rather than going straight to a Bill?

[265] **Dr Duncan:** The overall thrust of this all along has been that organ donation saves lives. We want to do more, so help us to get it right. The White Paper was asking questions around the different choices that need to be made in terms of implementation of the policy, and we believe that that now needs to be followed up with a draft Bill that puts more of a legal framework around that policy, together with more details in the explanatory memorandum. It is also then important that we take the wider public with us to say that this is not something that we are rushing and that we are going through a methodical, deliberative process to get the details right, including things like communications and the actual systems discussions that must take place. It is around making sure that we get it right going forward.

[266] **Mark Drakeford:** So, it is a combination of policy refinement and public education.

[267] **Dr Duncan:** Yes.

[268] **Mark Drakeford:** And that is why we are having this intermediate stage. I am sure that we will ask you back as part of our making sure that we are keeping as closely in touch with these debates as we can, so that when the Bill emerges later in the year we will be as well placed as we can be to do our job. Are there any final questions that anybody wants to ask? I see that there are not. Thank you to both of the witnesses. This has been really helpful.

12.00 p.m.

Papurau i'w Nodi Papers to Note

[269] **Mark Drakeford:** Yr eitem olaf ar ein hagenda yw eitem 4. Mae nifer o bapurau yma. Hoffwn dynnu sylw'r pwyllgor at un neu ddau beth.

Mark Drakeford: The last item on our agenda is item 4. There are a number of papers here. I would like to draw the committee's attention to one or two things.

[270] You may just want to have a glance at paper 5, because it has relevance to the session that we will have with the regulator, which will be part of our residential care inquiry. Some of the papers to note are genuinely just that, but that one will have something in it that we will want to come back to.

[271] Paper 7 is just to say that we wrote, as you know, as a result of the session with the

Older People's Commissioner for Wales, noting our support for the development of a UN convention on the rights of older people. The Secretary of State has replied, saying that, although the Government is supportive of these things in principle, it wants to pursue them by a different route.

[272] **Darren Millar:** I am not very happy with the response. I would like the committee to see whether we can do further work on that front and perhaps look at whether EU institutions, for example, might be able to draw up a convention of their own, separate to the UN, which appears to be quite slow in moving out of the starting blocks on full convention status.

[273] **Mark Drakeford:** Do you think that it would be useful to share the letter with the commissioner's office, to see whether it has any views on that point and why it preferred the UN route to the Madrid route, which we might be able to use?

[274] **Darren Millar:** Yes.

[275] **Mark Drakeford:** We can do that.

[276] Last of all, I remind Members that you have been asked for your travel preferences and so on for when we go to Wrexham in June. If any Members are able to go up the night before, there will be an opportunity to meet some people from an informal Age Cymru group who will be there before our formal session starts. People who will be coming up on the train in the morning will probably not arrive—at least not reliably—in time to take part in that. So, if anyone would like to meet that group, there will be an opportunity to do so. I know that Darren is able to do it, and I will be there, but if any other Members are available, you have a chance to do so.

[277] Thank you all; diolch yn fawr.

*Daeth y cyfarfod i ben am 12.02 p.m.
The meeting ended at 12.02 p.m.*