



Cynulliad Cenedlaethol Cymru The National Assembly for Wales

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

**Dydd Mercher, 29 Chwefror 2012
Wednesday, 29 February 2012**

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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

Eraill yn bresennol
Others in attendance

Sue Brown	Sense Cymru
Nancy Davies	Fforwm Pensiynwyr Cymru Pensioners Forum Wales
Haydn Evans	Fforwm Pensiynwyr Cymru Pensioners Forum Wales
Linda Thomas	Age Concern Caerdydd a'r Fro Age Concern Cardiff and Vale
Dr Rosie Tope	Pwyllgor Gofalwyr Cymru Committee of Carers Wales
Roz Williamson	Cynhalwyr Cymru Carers Wales
Rebecca Woolley	Action on Hearing Loss Cymru
Ansley Workman	RNIB Cymru
Phil Vining	Age Concern Caerdydd a'r Fro Age Concern Cardiff and Vale

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

Philippa Watkins	Y Gwasanaeth Ymchwil Research Service
Catherine Hunt	Dirprwy Glerc Deputy Clerk
Meriel Singleton	Clerc Clerk

*Dechreuodd y cyfarfod am 9.30 a.m.
The meeting began at 9.30 a.m.*

Cyflwyniadau, Ymddiheuriadau a Dirprwyon Introductions, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da. Croeso i chi i gyd i'r Pwyllgor Iechyd a Gofal Cymdeithasol. Yr ydym wedi derbyn ymddiheuriad gan Kirsty Williams.

Mark Drakeford: Good morning and welcome to the Health and Social Care Committee. We have received apologies from Kirsty Williams.

Ymchwiliad i Ofal Preswyl i Bobl Hŷn—Tystiolaeth gan Ddefnyddwyr Gwasanaethau, eu Teuluoedd a'u Gofalwyr Inquiry into Residential Care for Older People—Evidence from Service Users, their Families and Carers

[2] **Mark Drakeford:** Mae'n bleser gennyf gyflwyno ein tystion ar gyfer rhan gyntaf y bore, sef Nancy Davies a Haydn Evans o Fforwm Pensiynwyr Cymru; a Phil Vining a Linda Thomas o Age Concern Caerdydd a'r Fro. Diolch i chi am ddarparu tystiolaeth ysgrifenedig cyn y cyfarfod.

Mark Drakeford: It is a pleasure to introduce our witnesses for the first part of the morning: Nancy Davies and Haydn Evans from the Pensioners Forum Wales; and Phil Vining and Linda Thomas from Age Concern Cardiff and the Vale of Glamorgan. Thank you for providing written evidence before the meeting.

[3] Good morning, and welcome to you all to the committee. Thank you for joining us this morning to help us with our inquiry into residential care services for older people in Wales. This is the first of our main sessions where we will concentrate on the experience of different groups of people who have a part to play in residential care services and who will share their experiences and information with us. So, we are grateful to you. With four witnesses, we always struggle a little to ensure all Members who have questions have a chance to ask those questions they want to pursue with you, and to ensure that you all have a chance to tell us the things you need to tell us. I will probably look to Nancy and Phil to help me with choreographing it all to ensure that the right people are answering the right questions. We will offer you a few moments at the beginning for any key points you want to mention to us before we start. My aim will be to come back to you before this session finishes for you to be able to leave us with any final thoughts you think we really need to take away as part of this evidence session.

[4] **Ms Davies:** I would like to thank you on behalf of Pensioners Forum Wales for involving us in your inquiry into residential care. We have looked at the concerns that we have, what we think could be done about them and how it could be paid for. We have also sent you a basic framework of a care prevention plan, which needs to be padded out, but we feel that there is scope for keeping people out of care, and we need to look at it.

[5] **Mark Drakeford:** Excellent. You will see from our remit that we are just as interested in those services that help people to decide whether to go into residential care as we are in other aspects.

[6] **Mr Vining:** Good morning. Age Concern Cardiff and the Vale of Glamorgan is a charity that has been around for more than 30 years. In terms of working in residential care homes, our advocacy service has been going into homes for 15 years. We currently visit 48 local care homes on a regular basis. Our evidence is based on that regular interaction with care home residents, the things they have told us and the things we have observed in our

visits.

[7] Having read the evidence from the other witnesses, I can see that there are similar themes coming through. So, hopefully, some of those themes can be carried on after today.

[8] **Mark Drakeford:** Thank you. I now turn to committee members to start the question-and-answer part of the session. Does anyone want to make the first move? Mick?

[9] **Mick Antoniw:** I want to ask something about the reference in the papers to staff earnings. Does that impact on the quality of staff and of care? Is there a real concern that there is not the right level of quality and of training, and that the wages system within care homes impacts on that?

[10] **Ms Thomas:** Staffing levels are most definitely of real concern. For instance, people often have to wait after they press their buzzers to be helped to go to the toilet, and that is down to staffing levels. The primary objective of many care homes is profit, and, as we all know, staffing costs are usually the highest fixed cost, although the staff do not get paid a great deal, because there is, or should be, a heavy emphasis on staffing, as many hands are needed. Training is sporadic and, unfortunately, there is a high turnover of staff because of the pay and conditions. So, it is a vicious circle.

[11] **Mr Evans:** My experience of care homes is limited to occasionally visiting members of our group. I visited one in Cardiff about three years ago and, being a council and housing association-owned home, it was run fairly well. However, the staff are always under pressure and there is no time for interaction to any great extent between the staff and the residents, who are often old, frail or have dementia. You cannot consider these things without also considering the resources that are available for care. Without resources, there are not enough staff, and they are too busy. You then get to a situation that Judi Dench referred to lately as 'warehousing'—people scattered around the room, staring at the television or staring into space, where each day is exactly like the day before. No-one wants to enter that sort of situation at the end of their life, and that is why we all dread going into homes. So, until there are more resources in the system, there will not be enough staff to make life interesting for the people who have to live in these places.

[12] **Mick Antoniw:** In your experience, is there any variation in those issues between the not-for-profit sector and the private sector? With regard to the private sector, is there also a variation between the large corporate residential homes and the smaller ones? Does your experience lead you to any view as to variability across that sector?

[13] **Ms Thomas:** Yes, there is quite a considerable variation with regard to larger homes. I often say that we spent a lot of time and money taking away institutions for vulnerable people. It was deemed many years ago that it was unsuitable to have large establishments in which people were institutionalised, but it seems to be quite acceptable that we house our older people in those larger establishments. They are very depersonalised and are not a home environment; they are not places where I would like to put my loved ones, let alone myself. However, that then comes down to the business culture and economies of scale. So, that model is attractive for the provider because of the profit, but, for the individual, it is very depersonalised. Some of the smaller privately run homes are very good; you might say that they are a bit shabby chic, but they do have a more homely culture. As for the council-run homes, well, there are not any. There are some in partnership with other providers, and they tend to do quite well in terms of the levels of care.

[14] **Mr Vining:** It is interesting that, in general, our experience shows that the not-for-profit homes provide a better quality of care and more activities and that the residents are generally happier. Those same homes welcome our independent advocacy service, whereas

some of the private providers definitely do not want independent advocacy within the home, and, at the moment, they are not compelled to allow it in.

[15] **Darren Millar:** I was grateful for the opportunity to read your paper, in which you raise this issue of whether homes should be not-for-profit. Where is the evidence that the quality of care is poorer? Have you made an assessment of the care standards inspectorate's reports?

[16] **Mr Vining:** Generally, it is from going into homes every week for the past 15 years—visiting a good number of homes—and listening to what the residents are saying to us.

[17] **Darren Millar:** The difficulty for us as a committee is that we need to rely on clear evidence. If there are shortcomings in care, then that is an issue that we would certainly want to address, and the quality of care is something in which the committee is taking a keen interest. I am not aware, however, that there is a higher incidence of requirements and recommendations made of and to homes as a result of their being private businesses as opposed to not-for-profit organisations.

[18] You also refer in your paper to the fact that local authority homes have relatively higher costs, but that the quality of care is not better. Local authority homes are obviously not-for-profit enterprises, but you are saying that they have worse standards of care. So I am a bit intrigued as to how you have drawn that conclusion, particularly when you say that there are no local authority homes in the area, which means that you will not have had much experience of them.

[19] **Mr Vining:** The local authority homes have closed over the last decade. The remaining one in Cardiff is a specialist home for people with dementia. The point was made by one of our placement advisers, who, unfortunately, is not here today. That person's role is to support people in choosing a care home to go to from hospital. The point that I was trying to make is that the local authority costs are higher, but that the care is not necessarily better. What we are trying to say is that in homes run by Hafod Care in Cardiff and the Vale, for example, the response to our advocates is much more positive than it is in private care homes.

[20] I do not want to make a blanket generalisation, because there are some good private care homes and there are some good owners of private care homes, but surely there is an ethical question about making profits out of vulnerable people who need care. We saw what happened recently with the large care home groups, where shareholders' interests seemed to come before those of residents and families.

[21] **Darren Millar:** I am certainly not going to defend large care home groups that put shareholders before service users. I appreciate the ethical and moral dimension that you brought in, and some people do have an issue with the private sector being involved in the delivery of care. However, just on this issue of the quality of care being worse in those homes, I am not sure that I understand quite where that comes from. That is all.

[22] **Mark Drakeford:** I am going to ask Lynne to ask a question on this. Before I do, I will just say that I am pretty sure that a Social Care Institute for Excellence research paper in the last 18 months attempted to look at the quality of care by sector. I do not remember the detail enough to know whether it came to a conclusion that one sector was better in its quality of care, but I think that it would help with regard to your wider question if we could get a copy of that.

9.45 a.m.

[23] **Lynne Neagle:** Mr Vining mentioned the role of advocates in terms of their

experiences of the varying quality of care. I assume that there is a way for them to feed that experience back to Age Concern, so that you can establish some idea of patterns of problems and so on.

[24] **Mr Vining:** Yes, but we are a local independent charity. Where appropriate, we would feed things back to the management of the home, and perhaps to the Care and Social Services Inspectorate Wales, and to local authorities where they have contracting arrangements with certain homes. We look at the quality of care, so, we do feed things back and, when we have identified policy issues, such as the quality of care in private homes, we have raised them with the Commissioner for Older People in Wales on several occasions.

[25] **Lynne Neagle:** Are the advocates employed by you?

[26] **Mr Vining:** Yes.

[27] **Lynne Neagle:** So, as in any field where you are working with vulnerable people, the mechanisms are in place. Presumably they have supervisors and managers and you would be able to pick up trends if there were particular problems in a home.

[28] **Mr Vining:** Yes, certainly. Do you want to say that more about that, Linda?

[29] **Ms Thomas:** We work quite closely with local authorities; it is a two-way relationship. They can pick up potential concerns and we will then try to ensure that we had a presence in those homes. However, there is no obligation at the moment for homes to let us in, and that is another conversation that we have had. We feel that as part of the contracting arrangements between local authorities and homes there should be the proviso that advocacy, if available, should be allowed into those homes. That is of great concern to us. We offer our presence to any home in Cardiff or the Vale of Glamorgan on a one-off basis; we have approached many homes, but some have declined to allow advocates in, which has set alarm bells ringing.

[30] We are completely independent—we are there for older people—and we are realistic about what can and cannot happen in care homes. It surprises me that not every care home would want an independent advocate to ensure that concerns, if there are any, are raised. When we have taken concerns to managers, sometimes it is just that they were oblivious to them, and they have then remedied them. A fresh pair of eyes is sometimes needed to question why things are happening or not happening. That is the beauty of someone coming in from the outside. It can be a wake-up call for them, and they respond, ‘Yes, we could be doing that’. So, we are there to assist the homes and, more importantly, the people who live in them.

[31] **Lynne Neagle:** So, to clarify, if a home does not engage with the advocacy service, are there other ways by which the residents in that home can access the advocacy service? Could their relatives, for example, say that they want the advocacy service in, or is it a question of it all being down to the owner of the home?

[32] **Ms Thomas:** On occasion, we have been invited or asked to come in by a relative with a concern. We can go in on a one-off visit, because we cannot be stopped if a relative says that they want someone who is independent to come in to support their relative. The problem, however, with having an active relative with many concerns, who voices those concerns to the care home, is that they can be ostracised to the extent that their loved one may have to move. So, there is an advantage in having someone independent going in who does not take those emotions in with them and who can say, ‘Actually, this is what the person is saying; it is not their relative being overly critical’. So, we do go in in those cases, and we have never been refused on that basis, but we have been told, ‘No, we don’t think so, thank

you very much' when we have offered a regular visiting service.

[33] **Mark Drakeford:** There is a long list of Members wanting to ask questions, so we will have to move on to get through them all. The next three people to ask questions are William, Rebecca and then Lindsay.

[34] **William Graham:** I thank both groups for the evidence, particularly the 16 points from the pensioners forum, which was immensely helpful for the committee. Can you help me and the committee generally? I want to ask a question about the provision of information, first when the choice of care home comes about and then when people are admitted. What amount of information is given to relatives at that point? What has been your experience?

[35] **Ms Davies:** A lot of public information is not fit for purpose, because the people who provide it understand it and assume that the people who receive it will also understand it; that is often not the case. There is a tendency in all groups to use language that only the people who use it understand: doctors do it, teachers do it, lawyers do it, and I think that public services do it as well. This is an area that needs to be looked at, so that people are given written information in the same language as they speak. Many of our problems with children today and their poor language skills are that they do not learn to speak and, therefore, they cannot read or write. We need to look into this area of public information much more closely than we have ever done before, so that people get the right message from whoever is sending it.

[36] **Mr Evans:** I am aware of a case at the moment of a gentleman with Alzheimer's disease who is 56 years old. Social services have been trying to help find a suitable place for this person. He has a sister, and they have been helpful except that, at the moment, they do not seem to be keeping the sister informed of what is going on. She keeps leaving telephone messages and not getting any replies. So, it is important, even if the solution for a person of that age—who is not suitable to be warehoused with older people in the normal way—cannot be found quickly, that they at least keep the relative concerned informed. At the moment, the man is not happy where he is and needs to move somewhere more suitable. It is one of the difficulties that care homes face, namely that they are looking after different categories of people: people with dementia, people who are there because they are frail rather than because they have any problems with dementia, and, occasionally, much younger people who have Alzheimer's and cannot cope by themselves. So, it is a difficult problem from the care homes' point of view.

[37] **Mark Drakeford:** Phil, is there anything that you want to add quickly to this general question about the level of information that someone thinking about going into residential care is able to draw upon?

[38] **Mr Vining:** Briefly, I want to explain about our placement advisers, who are based in hospitals in Cardiff. Their role is to give as much information as they can to older people who face moving into care straight from hospital. It is a difficult situation, given that it is a crisis situation and there is pressure to free up the hospital bed and discharge the patient quickly, often in two or three weeks. As a result of the systems that they are working within, there is not a lot of choice of care homes, because a lot of it is down to the cost for which the local authority will contract. The last time that I spoke to the placement advisers, only two or three homes in Cardiff would work to that contracted price. So, unless you or your family are willing to top up the care home fees or you are a self-funder, there is little choice.

[39] On that point, the placement advisers have been there for about seven years, but they are only funded at the moment until the end of March, and it is looking a bit precarious as to whether that will continue. We hope that it continues, and that it can be replicated throughout Wales, because it is a time of crisis for older people and for the families who care for them.

They are often under pressure to make a choice very quickly and, as you have said, the information can often be presented in terminology that is not easy to understand.

[40] **William Graham:** I have a brief supplementary question, if I may. I am looking at the report on dignity for older people that was published very recently—I suspect that you will not have had a chance to read it, but I have one or two points on it. It says that discrimination towards the elderly is rooted in British society and that older people are often viewed as a problem to be solved rather than as equals. Does that chime with your findings?

[41] **Ms Davies:** Yes, and one of the main causes is the language that is used—‘bed blockers’, ‘living too long’, ‘living longer’, as well as discrimination against older people, which has today been pointed out in *The Daily Telegraph*. There is no other group in society that can legally be discriminated against, apart from younger people. We really need to be doing something about this.

[42] **Mr Evans:** On the communication point, it is right to point out the trauma involved for somebody coming from a Welsh-speaking community and going into a home that is largely English speaking. The problems of settling down and living with a lot of strangers, which is what you are doing when you go into a home, are aggravated by the change in language background.

[43] **Rebecca Evans:** I would like to take us back to Mr Evans’s earlier comments on activities in care homes. Could you give us some more information on how activities are organised? To what extent do they take into account the different needs and interests of individuals? Not everyone will enjoy the same kinds of activities.

[44] **Mr Evans:** The ones that I have seen have been craft activities, where people are encouraged to do things with their hands to keep their dexterity going. I have also seen mild exercise, to keep people reasonably healthy. Homes sometimes invite choirs in to perform for the people living there. However, there is not enough of this; the tendency is for each day to be the same as the day before, and there is not much stimulation for them. My feeling is that there should be somebody on the staff of every care home whose responsibility it is to think up activities or events that would help people to have a life rather than just to exist—to give them an interest. Somebody on the staff—perhaps even the manager—ought to be responsible for thinking up ways of stimulating the people who are cared for. After all, the people are paying to be there, so they are the ones who provide the jobs for the staff; self-funders are paying an awful lot of money to be there, so could reasonably expect a good service.

[45] **Ms Davies:** I am reminded of a few years ago, when I was still in the workplace, and we used to take children in to care homes. If they had been working on a concert, they would go in and sing to the people there. There would also be an invitation, through the grandchildren, to the older people living around the school to attend the concerts. There is currently a group called Live Music Now, made up of young musicians, which was devised to give young people experience in public performance. I saw some of them performing at the All Nations Centre at a conference about two years ago, and I was very impressed at the high standard of their performance. I think that they could be more widely used in care homes.

10.00 a.m.

[46] **Rebecca Evans:** To what extent are people asked what they would like to do and how they would like to spend their time? People enter care homes with a lifetime of interests, such as art, politics, gardening and so on, so are they supported to continue with these interests and to pursue them as an individual when they are in a care home? Or, as you suggested, is there a menu of activities that tend to come around and which are supported by community groups, churches and so on?

[47] **Ms Davies:** I have an aunt who is in a care home. She is 101 years old, and an event was held to celebrate her birthday, to which the family was invited. Everything went very well. She is encouraged to indulge in her hobby, which is hymn singing. She sings to the people in the room with her, and they often join in. People should be encouraged to make their own music, perhaps. I agree with what Haydn said, which was that you need someone in a home who is employed solely as a social officer to organise trips out for those people who are fit enough to go out. There should be little shopping trips to refresh memories of what they used to do. There are a number of possibilities, but you need someone to organise it, because everyone else is too busy. I have a friend whose son lives in America and, at one stage, that was his work: he was an entertainments officer in a care home. It is something that has been going on over there for quite some time.

[48] **Darren Millar:** I just want to follow that up. I am delighted to hear that your aunt is 101 and still singing hymns. I would like to ask about spiritual care, because it is something that does not feature in either of the pieces of written evidence submitted. As Rebecca has quite rightly said, many people will have had active interests in church or chapel life before going into a care home and, sometimes, can feel quite cut off from that unless there is an opportunity for some sort of spiritual care. It may not be religious care in that respect, but some sort of spirituality within the home. What are your views on that? Is sufficient spiritual care being given in care homes?

[49] **Ms Davies:** I doubt if there is sufficient fulfilment of this need in many care homes, but I know that, in the Valleys, it is quite common for the local vicar or priest to pop in. With the home that I visit, I sometimes go unannounced—I have no problems with this home at all—and I know that the local pastor pops in. However, I am sure that there is not enough of this, because many of these people are elderly themselves; I am thinking of my own vicar, who is now very frail, and would not be able to go into a care home to visit contemporaries. So, perhaps we need younger blood there as well.

[50] **Darren Millar:** What is Age Cymru's view?

[51] **Ms Thomas:** I would say that it varies, as do all of these things. That is the problem. We are not talking about blanket policies. I would support my colleagues' views on activities in care homes. This needs to come from the top. Very often, a care home will nominate a member of staff to become the activities co-ordinator, but, in reality, they are not given the time, the resources or the authority to do that. It is not just about activities, but the ethos within the home: it is about asking how someone is and what is going on and about the general interaction with people. This is sadly missing. Activities do not have to be several people sitting in one room painting or drawing; it can involve quick quizzes, and every member of staff should be engaging, perhaps asking whether they have seen something in the news—the kind of normality that we have in our daily lives. That interaction seems to be missing in care homes. Some people do not want things to be done to them, but the situation is variable; that is the problem.

[52] **Lynne Neagle:** Do you think that enough focus is given to the specific needs of people with dementia in terms of any activities that are laid on?

[53] **Ms Thomas:** We have recently been successful in getting some lottery money, because one thing that our advocacy service identified is that the make-up of older people in care homes has changed quite dramatically over the 15 years that we have been visiting them. In the early days, it was a care home; people chose to go there because they no longer wanted to cook or they were a bit lonely. Now, more people are rightly staying at home until they have to leave, and the demographics are such that elderly mentally infirm units are becoming predominant. Even residential homes are adapting to take on EMI residents. We are new to

that, although we identified the need, because we did not undertake what we call non-instructed advocacy. It is a different way of interacting with older people; you have to spend a lot more time with them and undertake many more observations. Watch this space; we will come back in another couple of years and tell you what is going on regarding people with dementia.

[54] **Mark Drakeford:** I have three Members who I am determined that we will fit in before the end of the session, so I am going to go to Lindsay next, then to Vaughan and then to Elin.

[55] **Lindsay Whittle:** I have about 20 questions, Chair, so I know that I cannot ask them all. I was interested in what Mr Evans said on the issue of the number of older people being grossly exaggerated by identifying those who are 50-plus as being older people. I want to declare an interest. [*Laughter.*]

[56] A lady in my village—she is sadly no longer with us—was 99 years of age and would often be seen striding through the village doing the shopping for those whom she called her older friends. She was remarkable.

[57] I am pleased that you mentioned Hafod Care Association. I used to work for Hafod Care Association, and I am sure that my former colleagues will be delighted by your comments. Do you have any examples of best practice in bringing people into homes? You make the point that, so often, people walk past some of these homes as if they are prisons. They are not prisons; they are people's homes. We will often pop in to talk to our neighbours, but we do not pop in to talk to the people in homes. It is almost as if they are forbidden territory. Do you have any examples of best practice?

[58] You also mentioned some figures. Somebody called Lord Taylor said that we spend £45,000 a year per head on prisoners in Wandsworth prison and £33,000 a year per head on young offenders. That money has to be spent, but do you have any figures on how much is spent on older people in care?

[59] **Mr Evans:** On the first point, if you want to see how it should be done, and you have plenty of resources to do it, visit the Sunrise Senior Living home on Cyncoed Road. Most of us could not afford to stay there; I will put it like that. That home has a notice outside inviting people to drop in for a cup of coffee at 3 p.m. or a cup of tea at 10 a.m.. I have visited a few times, and it really is like a home from home, where people come in and play games with the people who are living there. Even if they are suffering from dementia, people are still treated in a way that gives them the impression that they are still part of a community. However, that involves an awful lot of resources. Until we can find ways of raising more money to go into the system, we are not going to reach those standards.

[60] I thought that there was a good system when people who did not have dementia were first admitted to the home in Llanishen that I was visiting three or four years ago. They had rooms where three, four or five people would sit together during the day. They were like a little family. They took their meals together and they had a little kitchen where they could make their own tea. That was a homely atmosphere, but, as the people got older and dementia set in, I am afraid that they reverted eventually to sitting around the wall with the television on, gazing into space, which is, sadly, the most common situation that you will find if you visit a home.

[61] **Lindsay Whittle:** Do you have any figures? I will do some research if you do not.

[62] **Ms Davies:** I have some figures from the older people's commissioner that of 600,000 older people in Wales, 21,000 are receiving some sort of care, either in the home or

in a residential care setting. If you take those 21,000 and divide them into groups of 20, 19 of the 20 will be receiving care in their own homes, while the remaining one will be in residential care. I agree with Haydn about the exaggeration of the number of older people, and I have said to the Deputy Minister Gwenda Thomas that the threshold for becoming an older person is pitched far too low and that we will find, maybe in 20 years' time, that 70% of our population will be characterised as 'older people', which cannot happen.

[63] On your point about paying for care, we would never contemplate having a health service that was only paid for by the people who are sick. However, we have a care service that is financed by the people who have to use it. So, the only way forward for financing residential care is to have a national care service, alongside the national health service, funded from taxation. There are whole rafts of different taxes that could be robbed a tiny bit to provide a care fund, but it is most important that it is financed by everyone, because we do not know which one of us will need this care—we will not all need it, but about 5% of us will.

[64] It is only fair that a care service is financed in the same way as the national health service. It must be realistic, sustainable and there must also be a funded care pathway for everyone. If we cannot do as they are doing in looking after prisoners in their old age in Bridgend, Usk and Wandsworth prisons, then we have a serious equality issue in our country, which needs to be dealt with. I am sorry that I have gone on a little.

[65] **Lindsay Whittle:** It is the dementia issue that is critical, is it not? It is not about the fit older people, but those with dementia; that is the issue that I want to tease out.

[66] **Ms Davies:** We do not know enough about dementia. The experts—the people who know about it—need to give us more information about it.

[67] **Mr Evans:** There is a case for saying that we should not have care homes and nursing homes; we should have homes that care for everyone. Dementia is a disease after all—the people are sick, not just old.

[68] **Lindsay Whittle:** Yes, and you mentioned your 56-year-old friend.

[69] **Mr Evans:** Yes, my 56-year-old friend is on the way to becoming unable to care for himself. However, in a home that was both a nursing home and a care home, the gradual deterioration could be dealt with more easily. That would be better than trying to get the care homes to deal with people that they are not qualified to deal with.

[70] **Darren Millar:** That is an important point. There are some homes that are dual registered in terms of the type of care that they provide, because it is very unsettling for an older person who has significant needs to be moved from one place to another as their care needs change. I do not know what proportion of care homes in Wales have dual registration; it would be interesting to get that information.

10.15 a.m.

[71] **Mark Drakeford:** We shall find out. There is an increasing number of examples, such as the Hafod development in Bridgend, of residential care and a component of nursing care being provided on the same site, so that people are able to move more flexibly between the two.

[72] Lastly, on Lindsay's point, I think that it goes back to what you were saying, Phil, about the nature of residential care being different to the way that it once was: it caters for a much older, frailer population with multiple needs, of which dementia is clearly one of the big components. So, there is a big picture there. I am just going to ask Vaughan to come in before

we run out of time completely.

[73] **Vaughan Gething:** There are a couple of points on regulation in your evidence. Pensioners Forum Wales makes a suggestion that the care standards inspectorate should have a role in financial regulation and scrutiny. I am interested in how you think that might or might not work. What sort of information do you think should be provided? How would that then be monitored? How would that impact on the resources available to the care standards inspectorate?

[74] There are also comments in the paper from Age Concern Cardiff and Vale. When you say that the care standards inspectorate does not have enough power, what is behind that comment? Where do you think powers are lacking in relation to regulation and what would you like to see it have? Again, would that have an impact on resources?

[75] Following on from that, we have your statement that poor care homes should be named and shamed. Do you think that that would lead to an improvement in the quality of care in the sector? How do you see that sort of process affecting people who are already in the homes that are named and shamed? I think that there would be some difficult issues for us if we were to take that route.

[76] **Mr Vining:** Obviously, it is a complex issue. To give an example, we were visiting a private care home in Cardiff for an ongoing period, and we raised concerns about certain care issues at this home with CSSIW. We did that on two or three occasions. Its response at the time was to have a word with the manager and with the owner of the home, eventually. It kept requesting that certain improvements be put in place, and I think that some things were improved. However, others were not. To us, as an advocacy service, we were raising the same issues time and again, and there seemed to be no penalty for that home. It was clear to us that the manager of the home was under pressure from the owner to cut costs, to reduce the costs of the care staff. In fact, she was very reluctant to have the advocacy service there at all.

[77] What we are seeing is that it is very rare for a care home to be closed because of negative things going on there. We hear of care homes being closed because the local authorities have decided that they can no longer operate them, because they are no longer cost-effective or the buildings are not fit for purpose, but very rarely do we hear of CSSIW closing down a care home because of poor care, allegations of abuse and so on. It is only in very extreme cases, perhaps when things get into the media, that a care home is closed.

[78] **Vaughan Gething:** Before we move on, are you saying that there is an issue with the powers that the care standards inspectorate has, or are you saying that there is an issue with its approach to the use of its powers? They are different points, and I am not sure whether you are saying that it needs more powers or that you want it to take a different approach to the way in which it regulates private care homes, which is the example that you are using.

[79] **Mr Vining:** The role of CSSIW is changing and I believe that it is taking a different approach at the moment. I do not have all of the information on that.

[80] What we are saying in our evidence is that where we have raised specific concerns, they may be addressed in the short term, but in the longer term, those concerns will go on. I know of another home in Cardiff, which, because of the number of allegations of abuse in that home, the local authority placed an embargo on. In other words, it would not contract out any new beds in that home until it saw improvements. That went on for many years, with several embargos being put in place, but there never seemed to be a question of whether this home should be closed down. So, what is the penalty for such providers, who are obviously not providing good-quality care? In some cases, they are working to make a profit for larger companies, and there is no penalty for them.

[81] **Ms Davies:** While it looks at how best services can be provided, I wonder whether the Independent Commission on Social Services in Wales could take a role in regulating and set out the guidelines for regulating homes and monitor performance.

[82] **Mark Drakeford:** May I take it from that, in response to Vaughan's question, that you think that there is a need to look at how effective regulation is, as it currently operates, and whether or not it is doing the job that we want it to do?

[83] **Ms Davies:** There is always scope for regulation because otherwise we become complacent.

[84] **Mr Evans:** It is important that the inspectorate does spot checks or unannounced inspections. To pre-announce that it is going to make an inspection would give the home an opportunity to put things right temporarily.

[85] **Ms Davies:** They have already started doing spot checks in the NHS, so I agree with Haydn on that.

[86] **Mr Evans:** On the financial point, the concern is that if a home has to close down because the private sector company runs out of money, the people who suffer the most are the residents of the home. So, we would want every step possible taken to ensure that the homes will not suddenly disappear on financial grounds.

[87] **Ms Davies:** May I come in on that? I have been looking at the pathway for older prisoners, which is available on the internet, by Dr Sarah Walters. It occurs to me that the people who devised this have come up with something that we need to consider applying to everyone. May I just read some of the points relating to dementia?

[88] **Mark Drakeford:** Yes, but this must be your last point.

[89] **Ms Davies:** It states that all staff working with older prisoners should recognise mental health problems and dementia onset. So, we could look at that as a model for everyone, because it lists the points that the national service framework does not currently address and it is desirable that it does so.

[90] **Mark Drakeford:** Thank you for drawing our attention to that. You are right that there are interesting general themes to be learned from it. I am sorry that we have run out of time before being able to ask you to sum up any last points that you would like us to consider, but if, at the end of today's session, there are topics we did not reach that are important for the committee to bear in mind, we would be grateful if you could send us a note on those topics. Thank you for this morning, which has been interesting for us, and we are grateful to you all for having taken the time to share your experiences with us.

[91] We have one or two more colleagues who will be coming to sit at the table in the next few seconds. We will just give them a chance to do that, and then we will press on with the next part of our evidence session.

[92] Bore da a chroeso i chi i gyd i'r Good morning and welcome to you all to the
pwyllgor y bore yma. committee this morning.

[93] I am very pleased to welcome Rebecca Woolley from Action on Hearing Loss Cymru; Ansley Workman from the RNIB in Wales; and Sue Brown from Sense Cymru.

[94] We have been hearing in our last evidence session about the changing nature of

residential care, and the fact that it caters for a different sort of user than might have been the case some years ago. Obviously, we have had a chance to look at your evidence, which draws our attention to the fact that with that change in population comes a different set of needs that have to be addressed by residential care provision. Although we will hear from you mostly in relation to the joint statement that you provided on hearing loss and sight impairment, we know that many of the points you will make will be true of other types of conditions as well. We are grateful to you for your written evidence, and for being with us this morning. Briefly, to begin, do you have some introductory points that you want to draw to our attention, before we go to questions? Ansley, do you want to go first? Are you sitting in the middle for that reason?

[95] **Ms Workman:** The name plate was put there. If I may ask you a question, are we talking today about other things like early intervention, and sheltered care and extra-care accommodation? Do we have time for that?

[96] **Mark Drakeford:** We certainly have, in the sense that part of our inquiry is about the path that people take into residential care, and whether, if there were other possibilities open to people, different choices would have been made. We are interested in that dimension as well as what goes on once people have made that decision.

[97] **Ms Workman:** You will have seen from the evidence that all of our organisations have done research and have reports about what is happening in residential care. The main statement to make is that what we find is that sensory needs are not being met. People are going into residential care older and more frail because of early intervention, and the communication with these people in particular is not working once they are in residential care. If that communication works well in terms of finding out what their particular needs are, how to meet those needs, and checking that those needs are met, then that will make a big difference to people's lives. It is one of the fundamental things about people being in residential care, and it goes across the board, but there are particular strands within that communication to do with hearing and sight loss. That is probably one of the main issues that needs to be addressed.

10.30 a.m.

[98] **Mark Drakeford:** We will go straight into questions, as we will soon be running short of time.

[99] **Rebecca Evans:** I want to pick up on your first comment about the need for preventative measures to prevent people from entering residential care, or to reduce dependence on it. Could you expand on the type of preventative services that could help an individual with sight loss or sensory loss from entering residential care in the first place and the different ways in which that provision could be delivered?

[100] **Ms Woolley:** Certainly, there is a range of options available to people who are deaf and who may or may not have additional needs. We provide services, as do other organisations, which can help people to live independently in their own homes in environments that are familiar to them and that, therefore, will enhance their ability to communicate and to live a life that they might want to lead, rather than one that is constrained or reduced in some way. So, we typically talk about care and support services working in the community, which may involve anything from a few hours to 20 or 30 hours input for someone, to support them in their homes and in their own communities. Typically, the outcomes from those kinds of services can be really successful in terms of enabling people and allowing them to be independent for longer. So, we would advocate that those sorts of services were available to people. That is really quite important.

[101] **Rebecca Evans:** To what extent are they available at the moment? What barriers are there to people getting that service?

[102] **Ms Woolley:** It varies greatly between areas. Budget is a problem for many local authorities. We talk about local authorities commissioning these services—obviously, that will increasingly become an issue as we face times of financial difficulty over the next four or five years. So, we have significant concerns that that might bring reductions in people's services that are not necessarily made on the basis of an understanding of their need, but of the financial constraint of commissioning those services for them. So, that is certainly a barrier. Identification is another big barrier. I will not go into too much detail, because I am sure that Ansley and Sue will have similar points, but it is about identifying people in the first place and ensuring that they get that service. If we are talking about provision of suitable assessment—I know this is something that Sue will probably talk about in detail—understanding someone's needs and ensuring that the right service is provided for them does not always happen at the moment.

[103] **Ms Brown:** Speaking from a Sense perspective in terms of people who have both hearing and sight loss, one of the most common interventions we are talking about is something called a communicator guide, which does what it says on the tin; it is someone who is trained in communication methods and guiding techniques. There is the example in our evidence of the lady—and, unfortunately, this is quite common—who did not get any support at the point at which her hearing and sight really started to deteriorate. She lost all ability to receive communication because there had been no communication development, and she ended up in residential care, where still, no-one could communicate with her. Her situation was really quite serious. A number of care homes refused to have her because they thought she had challenging behaviour. So, we went in, taught her ways of communicating and everything was then sorted out. Had she actually had some communication development before she went into residential care, she probably would not have needed to go in and she would have been better off at home as she would have known her way around. If you take someone like that out of their familiar environment, their condition will deteriorate because they do not know how to get around the care home, as it is an unfamiliar environment. So, a small number of hours of support can help. Our staff who worked with her thought that, to start with, she might have needed two or three hours a day, but that could have gone down to two or three hours twice a week, to be able to keep here in her own home. She would have been happier there and it clearly would have been a much cheaper option in terms of state provision.

[104] I think that there are a number of problems. One is identifying that that support is available and knowing that there is something called a communicator guide and that there are ways to communicate that do not involve speech. Also, one of the big issues with identifying both single and dual sensory loss among older people is that they respond, 'Well, what do you expect? I am 82; of course I do not see or hear too well. It is only to be expected', and so there is no expectation that anything will be done about it. Older people themselves feel that way, as do their families. Too often, the professionals who work with them also feel that way. When we did our research in residential homes, we found significant numbers of people with hearing and sight loss that had not been identified at the time that they came into the home and had still not been properly identified by the staff, because the staff had not been given any training in it, so, of course, those people were not getting the support that they needed. Identifying that sensory loss and assessing what support might help would make a massive difference to those individuals and the people working with them.

[105] **Rebecca Evans:** My question is about whether old people either do not like to ask for help or do not like to admit that they are experiencing sensory loss. Is that a problem, and what can be done about it?

[106] **Ms Workman:** Yes, it is a huge problem. It is because people are afraid that they will be taken into care. That is a fear that people raise with us regularly. There are a few issues here, and one of them is about finding these people. If the services are not around to help people maintain independence, they will often be in their own homes, not seeing anyone from week to week, and services cannot get to them. If you have sensory loss and information comes through the door or through the television, you might not necessarily know that it is there. We know that there are some good information-giving services about; local authorities are really developing information provision and advice, and organisations such as Age UK will have a good information service. However, if you cannot read the information, how are you to know that the service is available? When we have set up services in an area, we have identified people who have never been known to services before, because nobody has come to them. They need someone to find them.

[107] We also have welfare rights officers who undertake home visits. There is a huge issue to do with poverty and people not claiming benefits. If people do not have the financial basis to live well, that means that they cannot afford to go out, to eat well or do all of those things that might prevent them from having to go into care because they are not living well. Our welfare rights officers refer people to other agencies. Our statistics for this year show that 28% of the people whom we have seen wanted to be referred to other services, whether that was social services for safeguarding issues, or local services that could provide social activities, befriending activities, or cover some other area of interest. That is a large proportion of the people whom we find. More work needs to be done to signpost people to the services that are available to them to stop them from getting into a position where they may need to go into care.

[108] I will give you a powerful example of somebody whom we heard about through another organisation and who was seen by our welfare rights service. The welfare rights worker turned up and there were two people, both with sight loss and both elderly. No heating was on in the house. They were lying in separate bedrooms with blankets over them. Both had cancer and just were waiting to die. They did not have the money to pay for heating or the links with support services for people to come in to help them. Unfortunately, that is a daily occurrence with regard to many of the people whom we see.

[109] **Lindsay Whittle:** What are your views on who does the assessment? Is it the occupational therapist or the local general practitioner in conjunction with the residential care home? Forgive me; I am only asking because I do not know.

[110] **Ms Workman:** There are many issues around the assessment process. Focusing on sight loss, in Wales, local authorities register the people who come to their attention. Around 1,600 people are registered in Wales according to Welsh local government statistics. However, there are 115,000 people in Wales who we know have sight loss that seriously impacts on their lives. So there is a disparity there. With regard to the assessment criteria, we are finding that many local authorities look at critical sight loss only; many people do not even get to the stage where they go to social services. Often, it is the case that many people are finding, or are found by, the local voluntary organisations such as ourselves, Age Cymru, and Action on Hearing Loss. These organisations are going out, talking to people and finding out what their needs are, but often recognising that they are not then referred to social services, because social services are unable, in the current financial climate, to provide services unless people are seen as having critical or substantial need. Therefore, most of the services that seem to be doing that early intervention work are in the charity and voluntary sector.

[111] **Ms Woolley:** Certainly as regards clinical diagnosis—identifying people who may not have acknowledged or realised that they have hearing loss or sight loss—we would expect GPs to make an initial gauge that somebody may have hearing loss and then refer them to

audiology for a full diagnosis. The way that those clinical services then interact with social care services is absolutely crucial, because the level of need that that person has may or may not mean that they need a clinical intervention, but they would almost certainly benefit from some kind of intervention as regards provision of equipment or assistive aids that would help around the home, even if they do not need, or are not willing to use, a hearing aid. Therefore, it has to be a holistic process, involving all of those individuals. If we are talking about somebody in a residential care setting, it is essential that the staff understand what the assessment process has been and what the outcome has been, so that they know how to implement the solutions—whether it be knowing how to clean a hearing aid or knowing that a person needs subtitles on the television. Unfortunately, many people would not even think about that.

[112] **Ms Brown:** As regards people with dual sensory loss, there is a piece of statutory guidance called ‘Social care for deafblind children and adults’, which says that a social care assessment should be done by someone who is trained to assess the needs of a deafblind person. Many people in residential care have not had proper assessments because the assumption is that, because they are in residential care, the job is done and everything is sorted. There is also an issue about people who come into older people’s social work teams not being identified as having sensory loss and therefore referred for specialist assessment, which means that they are missing out.

[113] **William Graham:** You have identified the problems very well; could you outline some solutions?

[114] **Ms Workman:** Do you mean solutions in terms of early interventions?

[115] **William Graham:** Yes, early interventions in particular.

[116] **Ms Woolley:** From a hearing loss perspective, the solutions are out there in the main, if only there could be greater provision of that nature of service for a broader range of people in the kind of care and support services that I have talked about already. For example, if it were not only those people who are deemed to have critical or substantial need who could access those services, we might well see a reduction in the number of people who need to be moved into a residential care setting. If you couple that with very early intervention strategies—which are probably outside the remit of this particular inquiry—that help people to acknowledge their sensory loss earlier on, you will find that it is a natural occurrence that people are getting the service that they need at the time that they need it, rather than waiting.

[117] **Ms Brown:** One of the things that would make a massive difference would be for everyone who works with older people to realise the numbers of people who have a sensory loss and to make that a priority—therefore, always to think about sensory loss and to ask whether a person has hearing loss or sight loss and, if so, to consider what they need to do about that, rather than just assuming that they are dealing with someone because they have dementia, arthritis or whatever, and to put sensory loss at the centre of what is being planned.

[118] **Ms Workman:** What has really come out in all of our different organisations’ research, as well as in academic research and good practice, is that sensory loss tends not to be at the top of any hierarchy. It is always dementia, for example, or other physical needs, and sensory loss seems to be seen as a side issue or an extra complication. People do not realise the huge impact that it can have on the other conditions, therefore the presenting needs and reasons for why people might have gone into care are seen as higher up in the hierarchy.

[119] **Mark Drakeford:** The RNIB has a current campaign to persuade the Welsh Government to make sight loss a public health priority.

10.45 a.m.

[120] **Ms Workman:** Yes. That is something that we are working really hard at, given that 50% of sight loss is preventable, which is just unbelievable. The figures are that around five people a day in Wales go blind. So, of those people, 2.5 did not have to go blind. So, that 50% is a huge figure. We are working to make it a public health priority, but there are a huge number of services available. Wales has done some fantastic things, such as the Welsh eye care initiative, which offers many things, such as free eye tests for older people, as well as the low vision service to help people maximise their sight. Many people do not know about that, and you may have great services but you must get the services to the people. Again, it is about getting the information out there and spreading the word.

[121] RNIB, in working comprehensively with our partners—and there is a lot of collaboration—is ensuring that anyone who comes into contact with us has access to everything else. Someone might ring up to say that they are looking for a talking phone, but we want to ensure that they will not leave only having the talking phone. We want to ensure that they know that they can come back and that we can refer them to befriending services or social services or any other service. It is about that joined-up working.

[122] **Darren Millar:** Thank you for your paper; I was particularly interested in two aspects. One aspect was the call for awareness training within existing care homes—you have, helpfully, listed some recommendations at the end of your evidence. The second aspect was to do with specialist residential care and whether you feel there is still a need for that, because it was not listed in your recommendations, but you have referred to it in the body of the report. You seem to be emphasising the needs of deaf people who use British Sign Language as their primary form of communication. With regard to the levels of awareness in most care homes, do you think that awareness training ought to be normalised in every home? Do you think that it should be regulated? If not, why not? With regard to the number of people who would benefit from a care home in Wales where BSL was the norm, as it were—for those culturally deaf people—how many people would benefit? Is that something you would advocate? I am not quite sure how many people in residential care have BSL as their first language.

[123] **Ms Workman:** It is mentioned in the report that Action on Hearing Loss Cymru, Sense and the RNIB are working together on a big piece of work in partnership with the Care and Social Services Inspectorate Wales and Care Forum Wales, because we recognise that this awareness is not there. We also recognise from previous research that just because you can raise an issue with care providers does not mean that they will do it. They have lots of pressures in terms of cost, resources and other things pulling on them, and many regulations and so on to meet. So, we decided that the best way forward was try to get CSSIW to include something on sensory loss within the inspection regime. That would then put an onus on the care homes to actually do something about it. So, we have been working with it and we have an agreement that sensory loss will be a part of the inspection regime from next year, which is a great piece of work, and we will train the inspectors. We are also working with Care Forum Wales, because we will need to provide some resources to registered care homes so that they are able to do it. We would see things such as awareness raising coming under that. If we do not have the structure in place to make it happen, it will not necessarily happen.

[124] **Darren Millar:** Would that be adaptations for people with sensory loss, such as contrasting-coloured light switches and so on?

[125] **Ms Workman:** What we wanted to cover under that was awareness raising. Doing training, providing information on the environment, communication and a person-centred approach would address all these issues in the care homes. However, they would not have to do it unless there was inspection, with someone coming along and asking what they had done

about this.

[126] **Ms Brown:** In the research that we did in care homes, we found that less than half of the staff who we interviewed had had any training in sensory loss. The ones who had, had training in hearing aids, but not in any other sort of equipment. They all knew about large print, but not about any other way of providing written information. The numbers of older people with sensory loss, either single or dual, are so large that no-one should be working with older people without some level of understanding of sensory loss, which is slightly different from the specialist issues around BSL users; that is a different issue. Acquired hearing loss and sight loss are so common that no-one should be working with older people without understanding them.

[127] **Ms Woolley:** On the issue of specialist care for people who are profoundly deaf BSL users, as you rightly said, our main paper did not specifically ask you to look at the report's recommendations, but I think that the additional information that we submitted stated that we would be grateful if you could look at those recommendations. The University of Manchester study specifically looked at the problem of incidence. There is a relatively low incidence of profoundly deaf BSL users in Wales, and the geography of Wales would make it quite difficult to look at how we would prioritise the set-up of specialist homes. However, that does not mean that it should not happen.

[128] One thing that is clear in the paper is that that incidence might rise over time as other services for profoundly deaf BSL users are set up. If you set up a service, people will naturally identify with that service and therefore you will realise the level of need that exists. We also need to consider the fact that the population that will access residential care in the future may be a population that is much more willing to express its needs. We will see that reflected in the BSL-using population, as with the hearing population. So, there will be a group of people who will be saying, 'I want my needs met: these are my specific needs'.

[129] If we are talking about awareness raising, we are not talking about a homogenous group with regard to hearing loss or any other kind of sensory loss. So, while we are talking about age-related deafness or any other kind of hearing loss, we should also be raising awareness of the cultural issues for people who are profoundly deaf BSL users, so that care home staff understand that that group has very particular needs. I am sure that we would say the same thing about some of the services that Ansley and Sue are more specifically aware of as well.

[130] **Darren Millar:** I would have expected the prevalence to be quite low, given that there are not huge numbers of people using BSL in Wales. However, how low is it? Are we talking about 20 people across Wales who use BSL as their first language who require residential care, or are we talking about 25 or 30?

[131] **Ms Woolley:** I do not know, and I am not sure whether a piece of work has been done to that level of detail. We have the same problem in identifying the number of people who are profoundly deaf BSL users, given that many people are not registered as such. So, I do not know the answer to that question. All I know is that the academic research tells us that prevalence is so low that it might make it difficult, or render it unacceptable, which is the word that was used, to set up such a service.

[132] **Darren Millar:** The interesting thing in the paper is that people currently have to be sent quite some distance into England and other places, well away from their home and their support networks—their families and so on—to receive the residential care that they need.

[133] **Ms Woolley:** That probably goes back to the point that we made earlier about alternative solutions and what more can be done in a preventative and community-based

form. Another thing that comes through in the paper is that that is what people would prefer in any case.

[134] **Darren Millar:** So, you would rather see the emphasis on that than on a residential service?

[135] **Ms Woolley:** Yes, absolutely.

[136] **Mark Drakeford:** While I check with colleagues about who wants to ask the next question, could I ask whether you have any views on a point that was raised by our last set of witnesses? Given the increasingly frail nature of the population that enters residential care, is the distinction between residential and nursing care a sensible one for the future? It was in the past, but would a more flexible or seamless way of caring for people who enter residential care either with a long-term sensory impairment or as a result of developing an impairment of one sort or another as they got older, be desirable, as opposed to maintaining separate regulatory and registration regimes and so on for these two different sorts of services?

[137] **Ms Workman:** I do not think that we have a RNIB policy view on that; it is about getting the model right, whether that is nursing care, residential care or whatever. In some ways it does not matter, because it is about the service that is provided within the model and whether it meets people's needs. So, as an organisation we do not have a particular view.

[138] **Mark Drakeford:** Sorry, I was probably being a bit obscure. The point was made to us last time that, at the moment, if your needs reach a certain threshold, you may have to move, and perhaps some distance away, because you now need nursing care, whereas a more flexible model might mean that we would be able to have greater continuity of care for individuals. Is that something that you think is important to people?

[139] **Ms Workman:** Absolutely. We were talking about examples from England earlier, and it is the case that you do not get to see the same people. There is no continuity, and nobody knows you and exactly what your needs are, which is absolutely crucial to get the quality service that you need.

[140] **Ms Brown:** As we get an increasing emphasis on people staying in their own homes if they possibly can, there will be less and less need for residential care for people who do not have more complex needs. The message from this evidence, I would say, applies whether we are talking about residential care or highly specialist nursing care. The issues for people with sensory loss will be exactly the same.

[141] **Rebecca Evans:** To what extent are activities in care homes accessible to people with sensory loss, and what could be done to improve things?

[142] **Ms Workman:** They are generally not accessible—that is the evidence that we have found. To take an example, we do work in sheltered and extra-care accommodation, and, even there, where people are more independent, the activities are often not accessible to people with sight loss in particular, so when you step up a notch to the registered care homes, then it is even less likely that there will be accessible activities. One thing that we suggest is to link into what is already there in the community, and bring in your local organisations. A prime example in Cardiff is what everybody knows as Cardiff Institute for the Blind, which is now Cardiff, Vales and Valleys Institute for the Blind. It goes into registered care homes and offers befriending support, and peer support, and brings activities in, but it is also able to talk to the staff in the homes about the kinds of activities that are on offer, and what adjustments need to be made for people with sight loss. It can be really simple things—the obvious thing that people think about is large print books, but, nowadays, we are talking about care homes with Wii Fit, and all those different types of things. Digital technology and iPads are

incredible for people with sight loss. They are fantastic. Things such as that are used by the general population and more and more by older people, so why are we not using things like that? They can use it to connect to families through Skype and Facebook and all these different types of things. If you are interested in quilting, or whatever, it is all there. So, there are those very simple things in terms of engaging with the outer world, as well as bringing other organisations in to help support people with sight loss.

[143] **Ms Brown:** We interviewed people with dual sensory loss and asked them specifically about social activities, and what they said was that they struggle with group activities, yet almost everything that was organised in their homes was a group activity. They really wanted more opportunity to do one-to-one social activity, because they just were not able to engage. It is quite common that people get seen as being a bit stand-offish, and people say, ‘Oh, she doesn’t want to engage’, and sometimes that is not because they are being unfriendly—it is because the activity is not accessible because the room is too noisy.

[144] **Ms Workman:** Also, if you do not understand someone with sight loss, then how can you construct an activity that they can get involved with? It could be that somebody has only central vision, so staff would have to stand in a certain position, and activities would have to be planned in a certain way. There is a general assumption that, if somebody has sight loss, it is a kind of general sight loss, and nobody knows that it is specific to that person and what that means in terms of how they engage.

11.00 a.m.

[145] **Darren Millar:** I have one final question. In terms of the work in the community, I am pleased to hear that the Care and Social Services Inspectorate Wales will feature sensory loss as an issue within its inspection regime. However, one point that you raise in your report is the need for regular eye and hearing tests. How often are those undertaken for people in residential care? Could you tell us whether that will feature in the inspectorate’s regime in the future as part of your discussions with it?

[146] **Ms Woolley:** I think that Sue has some useful data on this. From our perspective, in terms of people with hearing loss, we have recently done research that is about to be published in which we discover that the incidence of people with hearing tests in residential care is quite low. That research specifically screened people and found a very high number of people with hearing loss who did not realise that they had hearing loss and therefore had done nothing about it.

[147] **Darren Millar:** So, you would like it to feature in the inspection regime, for example, that everyone must have a hearing test every two years or annually or whatever it might be?

[148] **Ms Workman:** Absolutely, but we would go a step further, which relates to work that we are doing on learning disabilities and sight and hearing loss. You can get the test done, but then someone has to do something about it. So, it is about the follow-up and addressing the fact that, say, Mrs Jones has this particular eye condition and therefore needs to wear glasses, which will provide her with a much better quality of sight. However, you have to get some people used to wearing glasses. Therefore, we need to think about how we work with those people: how staff communicate and plan things. Hopefully, in that person’s assessment plan, we would be able to see the outcome relating to that person’s hearing or sight loss in terms of what will be done about it.

[149] **Darren Millar:** So, when someone is assessed prior to being admitted into a residential care setting, is an eye or hearing test routinely conducted as part of that? Should it be or should they at least have had such a test within the last 12 months?

[150] **Ms Workman:** I should say so.

[151] **Ms Brown:** That should be a relatively straightforward thing to check when it comes to inspection—when that person last had an eye check and what the result was. The same is true of the hearing test. Just because someone had a hearing test and was given a hearing aid, it does not mean that they do not need to be rechecked, because their need for hearing aids will change. There is an awful lot of evidence that people with hearing aids do not use them. There are various reasons for that, but one will be because the aid was suitable for their hearing 10 years ago but they have not had another test to see whether that aid is still suitable.

[152] **Ms Workman:** There is also an issue about the fact that staff may not necessarily regularly check and clean the hearing aids.

[153] **Ms Woolley:** Absolutely. We are talking about the assessment actually informing someone's plan for what happens to them while they are in that residential setting. Generally, the level of awareness among care home staff about how to maintain hearing aids—and other pieces of equipment, I am sure—is really low. I was with a group of care home managers a month ago and they quite openly said that their awareness of such issues was low and that they did not know what to do and neither would many of their staff know what to do. It is a really significant issue.

[154] **Ms Brown:** We include in training for staff about hearing aids the following little mantra: is it on, is it in and is it yours? The fact that you have to start at that level gives you an indication of what the issues are.

[155] **Mark Drakeford:** Thank you all very much. You have given us some very clear messages in the last 40 minutes or so. We have a couple of minutes before we break to check whether there were any questions that we did not ask or any points that you did not have a chance to raise this morning that you think are important for us to be aware of as we take the inquiry forward. Are there any final thoughts that you want to leave with us?

[156] **Ms Workman:** I would briefly mention the sheltered and extra-care accommodation. Wales is ahead of the game on sheltered and extra care. We have seen the numbers in registered care homes going down and those in sheltered and extra-care accommodation going up. That makes a tremendous difference to how services are provided and to maintaining people's independence. The RNIB works with 10 associations in Wales, with around 100 properties. There is an accreditation scheme on raising awareness of sight loss relating to the built environment and how people work and health and eyecare messages. For us, that would be one of the models, if people were not able to be maintained and supported at home, as a step before registered care homes. We have done well so far in Wales on that, and it can be built on.

[157] **Ms Woolley:** I have just a quick note about prevalence. The information that you have in the papers we have submitted is sufficient, but I would draw your attention to it again. The projections around the prevalence of people with sensory loss over the coming years are stark, and the message that has come through from all of us is that the need to acknowledge sensory loss as a fundamental part of the assessment or the route into residential care and to plan earlier intervention will only become more important.

[158] **Ms Brown:** I would echo that. If you are looking at anything to do with older people, you need to put sensory loss at the centre of it.

[159] **Mark Drakeford:** That is a good message to leave with us. Thank you very much for coming here this morning. A transcript of the evidence will come to you, for you to check that

it has been accurately and faithfully recorded. Thank you very much for your time and expertise.

[160] Fel pwyllgor, cawn egwyl fach yn As a committee, we will now take a short
awr. break.

*Gohiriwyd y cyfarfod rhwng 11.06 a.m. a 11.18 a.m.
The meeting adjourned between 11.06 a.m. and 11.18 a.m.*

[161] **Mark Drakeford:** Bore da, a **Mark Drakeford:** Good morning, and
chroeso i'r Pwyllgor Iechyd a Gofal welcome to the Health and Social Care
Cymdeithasol. Committee.

[162] I welcome Roz Williamson from Carers Wales, and Dr Rosie Tope from the
Committee of Carers Wales. Thank you very much for coming here this morning. As you
know, we have been spending our morning looking at the experience of users, families and
carers in relation to residential care services for older people in Wales. We shall follow our
normal format. We invite either or both of you to make any brief introductory remarks that
you might like to offer us. I will then go to Members, who will have some questions that they,
I am sure, will want to explore with you. With a bit of luck, towards the end, I will be able to
come back to you to see whether there are any final points that have not emerged as strongly
as they might have done from the session, so that you do not leave without us knowing about
them. We will start with you first, Roz.

[163] **Ms Williamson:** I have agreed with Rosie that I will do just the very basic stuff.
Rosie will give the main introduction or presentation.

[164] I am the director of Carers Wales, and I think that many of you know that we are
basically a campaigning organisation that has a membership of family carers. It was set up
originally about 40 years ago to provide support for the 6 million or so people across the UK
who support family members, friends and neighbours. We believe that caring is absolutely
part and parcel of ordinary everyday life; it is not an exceptional activity, but a normal
activity. We will all do it at some point in our lives. However, we also believe that there are
serious issues for a significant group of carers—about 90,000 people in Wales; 120,000
provide care for more than 20 hours a week, and 90,000 for more than 50 hours a week—
about how the level of their caring role impinges on their ability to have an ordinary life. So,
we believe that caring should always be a free choice and that people should be supported to
do it. About 97% of all community care is not provided by social services or the health
service; it is provided by family members. That is absolutely key.

[165] In terms of the residential care issue, our membership is primarily people who are
fighting tooth and nail to support their family members, the people whom they love, in their
own homes in the community. However, inevitably, with certain illnesses, conditions and
frailties, that is no longer sustainable. The main thing that Rosie will talk about and share a
little more experience about is that, usually, those are crisis situations in which decisions have
to be made quickly, which have all kinds of repercussions for the person who goes into the
residential setting and for the family carers at home. Rosie has extensive personal experience
and professional experience and has worked with a lot of family carers, so I will hand over to
her.

[166] **Dr Tope:** Good morning, everybody. As Roz has just said, I am here with two hats
on: mainly as a carer of my husband for the past 12 years, who is now rapidly reaching the
end of his life with dementia; I also have a healthcare background, as did he, so you could say
that we were very much an informed carer and recipient of care, and we were

privileged, I guess, at the start of this journey, to know which boxes to tick, which numbers to ring and how to use the system to full advantage. I need to make that point clear, because, with my professional hat on, I have interviewed carers and people with dementia—I was looking back through my notes and I have interviewed more than 1,000 people as part of various projects since 2009 alone. What I would like to do today is to talk about the issues and key points, but not specifically relating to dementia, because I have also done a lot of interviews related to families with children and young people with complex disabilities and people with chronic degenerative life-limiting diseases across the adult span. However, inevitably, my personal experience will come into what I have to say. Rather than give you lots of statistics and data, which you doubtless have been receiving, I have had a look back through my records, and I thought I would give you potted case histories of where things can go terribly wrong.

[167] I should also make it clear that one of the first things that my husband did—he diagnosed himself, really, but it was confirmed in February 2000—was to put in writing his wish to waive his anonymity, so that we could talk quite freely. He has spoken at conferences in the UK and abroad, and so have I. We have also used what is almost a photographic record, which I continue to use, in which his head or face are never blanked out. His case is being used in medical and dental schools and all sorts of places, because that is what he wanted. So, I give thanks to him for that.

[168] As Roz said, in most circumstances, the bond between a service user—if I call them that, if it is acceptable across the board—and their prime carer is normally very tight. They are an integral unit and they have an unbreakable bond, particularly when they are life partners. So, acknowledging the bond and respecting those choices is the starting point for me, with a professional hat on, in any inter-agency discussion, case conference and so on. The service user and their carer are right in the middle; that is absolutely essential.

[169] What has been extraordinary to me is thinking that you know it all, with your professional hat on, and just how startling some of the things that happen are, and you have never really thought about it before and you have never experienced it. I certainly did not expect to react the way I did when, after nine years of looking after my husband at home, it suddenly escalated into a crisis situation when he became acutely psychotic and extremely violent over a period of a few days. It was more than a week before either of us slept. Neither of us went to bed; we were running around, I was trying to keep safe and trying to keep him safe, so it was a crisis situation. He was admitted immediately to a safe environment, which was a hospital environment. Luckily for us, because I then had power of attorney, he went in as a voluntary patient.

[170] This is another key thing that I want to say about people at the start of their journey—they do not realise what is coming. It was so important for his dignity, as disturbed and distressed as he was, that he went in as a voluntary patient. Many of the carers that I have interviewed say that people with dementia, if they are deemed to have lost capacity, are very often taken into hospital under the Mental Health Act 1983, against their wishes, and most certainly against the wishes of the carers. Some of the carers that I have talked to say that although it happened several years ago, they are still incandescently angry because they have had the experience of seeing their loved one effectively taken away by a crowd of people from their home. That is their lasting memory. For me, it was a question of me and him, along with the helpers that we needed at that time, walking out through the front door together. We went together to the hospital and he carried one of his bags with him. To me, of course, that was still heartbreaking, but it was not the same experience as many other people have.

[171] What I wanted to say, related to that, is that too often, for people living in the community—most people want to stay at home and most carers want to keep their loved one at home, without any doubt—it is a reactive intervention to a crisis situation. That may

involve dementia, children or young people with complex disabilities or adults with degenerative diseases. Something happens, then the whole pack of cards tips over and they are gone. Most people also harbour the hope that their loved one is going to be able to come home again when things stabilise. People are quite realistic that people are not going to improve or get better, but those issues are important.

[172] On taking people to residential care or nursing home care, it is inevitable that there are transferrable issues across any form of care away from home and I wanted to highlight those. For example, in one case study, there was a guy with dementia whose wife had a recurrence of her cancer, and both were elderly, so the question was who was looking after whom at home. There was a case conference and, after 56 years, they were split up: one went to a residential care home because they ticked the right boxes, while the other went to a nursing home. From the day that they left home, because the wife died three months later, they never saw each other again.

11.30 a.m.

[173] I cannot bear to think about how it must have been for them. When I spoke to the lady concerned, the heartbreak was awful to hear about. I was supposed to have a professional hat on during that telephone interview, but you just want to reach out and ask how that can be allowed to happen. We have to rethink these sorts of things. I have plenty more examples.

[174] **Mark Drakeford:** That was a very powerful beginning to the session.

[175] **Darren Millar:** First, I thank you, Dr Tope, for sharing your personal story. It is important, as we look at these issues as a committee, that we realise that we are talking about people's lives; you brought that home to us today, which I appreciate. The point that you made about married couples is a powerful one. I agree that it is unacceptable that people are split up. One of the issues that we have been discussing and have been asking witnesses about is whether there ought to be more residential care settings that are dual registered for both residential and nursing provision, which would possibly help to overcome the sort of situation that you are talking about. I would appreciate your views on that.

[176] There are two additional issues on which I would like to hear your comments. You have mentioned crisis situations as often triggering the need for somebody to go into residential care. What can we do to help prevent those kinds of crises from arising? To what extent does respite care help to recharge the batteries of carers to enable them to care for longer periods of time in future? You will be aware that the National Assembly for Wales took forward the Carers Strategies (Wales) Measure 2010 a couple of years ago. Some of the issues that were discussed as part of that process were around communication with carers about their loved ones and so on. This nut of respite care has never really been cracked. Do you have any views on that, as members of Carers Wales, and from your personal experiences, Dr Tope?

[177] **Ms Williamson:** The issue of respite care is crucial. The nature of respite care is something that we have not really cracked yet. Rosie and I have talked about some examples and I have also had several phone calls on this issue this week, because I think that people knew that I was coming to speak to this group. A caring situation can break down and somebody will have to go into residential care for two reasons: one is that there is a crisis with the person who is ill or who has the condition and the other is that there is a complete breakdown in the health of the carer. One of the purposes of respite care needs to be to maintain the health and wellbeing of the carer sufficiently so that they can continue for as long as they feel that it is right for them to do so and right for the person who they look after.

[178] One of the problems is that I do not think that there is enough planned regular respite

at present in Wales that is longer than two or three hours, which is, basically, so that people can go to see their general practitioner. Although that is important in order to maintain their health, people who are in a very heavy caring situation need to know that, every six weeks or so, they can have a weekend or three days off, or something like that.

[179] Not everybody is in a spousal situation, so you may be caring while living in a different country, as I was while caring for my father. My brother was obviously the main carer, but both his parents-in-law also required care. His first three grandchildren were born within three months of each other, and his wife had an operation. The bit of the jigsaw that I tried to provide was going over every other weekend, or every third weekend, to give him the week off. If there are no other family members who are able or willing to do that, somebody else has to do it; nobody can do it seven days a week, 24 hours a day, particularly if they are also in paid work, which half of all carers are, or they have other family responsibilities. You do not usually have a relationship with just one person; you may have teenage children, or grandchildren that you provide childcare for. So, it is very complicated. For the Assembly and everybody else to think about 'good enough' respite that will mean that people can plan their lives and know that they can get the breaks they need, when they need them, is a massive challenge.

[180] **Darren Millar:** To follow that up, as I understand it, there is no absolute right to respite for anyone with a caring responsibility. Clearly, people's needs will be different, so it would be daft to suggest that there might be a minimum respite provision that would be applicable to everybody, because some people will require less than others. Some elderly and vulnerable people might require every other day off, while other people might need a fortnight a year or whatever. Do you think that those sorts of things ought to be specified from the outset? That is, when someone has a caring responsibility, do they need an assessment for themselves in the same way that the needs of their loved one might be assessed? Should that assessment include something on respite provision for that individual?

[181] **Dr Tope:** Yes, I do, and, yes, it is happening now. I took on the official role of carer in February 2000, having received the confirmed diagnosis, and, on the very same day, we saw a social worker. We went from diagnosis to that, which was great. The next time that we had any contact from social services at all was in 2008, when I was screaming my head off—I was saying that my husband was falling at home and that we needed handrails, and we needed some sort of assessment. I then discovered that I should have had a carer's assessment as well. Having then pushed all the right buttons, and having phoned everybody to ask what was going on, I was no. 27 for the carer's assessment, and there were—I have forgotten how many—thousands more to go, because they were trying to play catch-up. When I phoned social services, the person I spoke to asked when the diagnosis was, and I said, 'We saw you in 2000, and this is who we saw', and there was a silence. And then, how lucky, there was a cancellation the following day, so they came round to do the assessment and the things were in place by the end of the week. Now, something tells me that that was because they realised that we had fallen into an abyss somewhere and that we were okay because we knew what we were doing. We were not okay; we had just carried on. However, everybody has the right to a carer's assessment and a response thereafter.

[182] **Darren Millar:** That is a very important message about the fact that crises can arise for two reasons: one is a deterioration in the service user and the other is a deterioration in the health of the carer. I therefore think that respite surveys are needed.

[183] **Dr Tope:** May I mention a case that came up in the last few weeks? It illustrates that point beautifully. Somebody I know has early-onset dementia; he is in his late 50s. He is coping well, with support at home, and is leading a very active life at the moment, night and day. He constantly enjoys being out and about—I know the couple very well.

[184] My husband remains in continuing care in a hospital setting, three years after he was admitted, which is the right place for him. However, I was absolutely astounded to walk onto the ward one day and think, ‘What on earth?’, because I had seen this guy out and about only a week beforehand. I wondered what crisis had happened, but it was nothing to do with him; his wife had suffered a complete and utter breakdown, so much so that she had been an emergency admission to hospital, which meant that he had to go to somewhere immediately, which was somewhere that had a bed available because someone has just died. So, he is in a place that is entirely the wrong place, but he is safe and well cared for, but the awful thing is that you do not know how long this will be for. If you have had a complete breakdown, it is not like having quick surgery and 10 days’ rehabilitation and off you go again, because it could take months. The tragedy is that when this lady recovers and is well enough to leave, you cannot imagine that she will be able to take up where she left off, particularly as his disease is ongoing. You hear a number of cases like that time and again; it is the carer that cracks.

[185] **Mark Drakeford:** Quite a few Members want to ask questions in the 20 minutes that we have left, so I will go to Lindsay, Rebecca, William and then to Vaughan, if their points have not already been covered by then.

[186] **Lindsay Whittle:** Thank you both for your evidence. Where would be in Wales without carers? Wales would probably close down without them, if we are being honest. I am interested in the emotional and psychological impact on individuals and their carers of moving to residential care. I am sure that some carers feel that they have failed, and, of course, nothing is further from the truth. With regard to your story, Dr Tope, I have such admiration for you and your husband; it is a most remarkable story, and you both are truly amazing people. Who, in your opinion, should care for the carer at that critical time? Should it be social services, the occupational therapist or the health authorities? Where does the emotional support come from? We have this overreliance in Wales on the voluntary sector. Do you think that we should insist on some legislation in this regard? We have new law-making powers now in Wales, so should we insist on some legislation to ensure that someone cares for the carer? The support needed must be phenomenal.

[187] **Ms Williamson:** The biggest problem for carers getting any support, at whatever point in the journey they have reached, is that they do not think of themselves as carers. I do not necessarily think that it is the primary purpose of the statutory services, so the voluntary sector is crucial. I do not know everything that the Alzheimer’s Society does, but for those kinds of particular illness groupings, charities are crucial, because they will, by and large, be able to put people in touch with people who have gone through the journey.

[188] Very small things can make a difference. I will give you an example from my family’s experience. When my father’s care plan was being reviewed, my brother and I said that we were committed to keeping dad at home as long as it was absolutely possible and as long as he was safe. The social worker said that she could see that that was what we wanted to do, but she gave us one piece of advice, which was to start looking at care homes now, because, otherwise, when the crisis comes, as it inevitably will, we would at least have identified a home that would be the best place for our father. Otherwise, he would end up wherever there was a bed. That was a piece of basic advice, but we as carers felt safer that we had looked at several places and put names down. As she said, it does not matter if he is not ready to go, because all care homes will say, ‘Fine, but do you want to stay on the waiting list?’, and that made a huge difference to me and my brother, knowing that we had done the work and that when the situation arose, we did not have to do it in a panic. We could just ring around the places we thought were acceptable until we had a good placement. That is basic advice that social workers, care workers and statutory services could give. The emotional support will still, I think, come by and large from peer support groups—the Stroke Association, Alzheimer’s Society, Parkinson’s UK—because it is the talking to other people

who have lived through it that is most important.

11.45 a.m.

[189] **Dr Tope:** The other thing, for me, having interviewed so many people, is that if you ask them what makes a good care home, the usual response is ‘Really nice staff’. I have quote after quote that says, of the staff, ‘They’re lovely’, or, of their loved ones, that ‘He/she always smells nice and clean’. It is most important to have those boxes ticked, but then you have things such as, ‘The only problem is, though, since he has been admitted there, he has been in bed all the time’. ‘How long has he been there?’ ‘Five weeks’. In contrast, you have, ‘Having been transferred in from somewhere else, he was up every day’. That person may be chair bound, but he was up every day. So, they are upset that they are in bed all day and every day, but they do not think to ask why that is or think, ‘That can’t be right’. It raises questions in my mind about staffing levels, safety and many other things. Carers do not know what to look for in a good residential or nursing home; it is all about people being nice and the place smelling okay. They need clear advice, and they need help for when they go to see one.

[190] **Mark Drakeford:** A point made in evidence by other people is that, so often, these are decisions that you make once in a lifetime. You do not have a hinterland of previous experience that you can refer to so that you know what to look for when making these judgments the one time you will be doing it—or twice at most. So, having that sense of what to look for and how to make a judgment is not something that is easy for people to acquire.

[191] **Rebecca Evans:** I have two questions, the first of which follows on from what Dr Tope was just saying. To what extent are families and carers able to be involved in the care that their relative receives in the care home setting?

[192] The second question is related to that. To what extent are families and carers able to be involved in the lives of their loved ones? That is a different thing from their care. Are they able to maintain the lifelong family relationships?

[193] **Ms Williamson:** That is one of the biggest concerns. I should say that we did not submit written evidence before Christmas because we did not think it a huge issue for our members. Of course, now that we have been talking about it a bit more, we realise that it is. It is very important that people feel that they are still the primary carer for the person they look after. In some settings, there is an idea that people are just glad to get rid of the responsibility, and of course, they are not; they still feel that that is their primary responsibility. They are very glad that tasks have been taken off them and that the person is safe.

[194] A really good home will make sure that that bond is kept as close as possible and that the expertise of the person is listened to and acted on. As you say, it should be easy for people just to pop in and be with a person as and when. That was certainly my experience at the home that my father went into: it had an open-door policy. I think that staff only locked the outer door at about midnight. This meant that my brother, if he was coming back late from somewhere, could just pop in, stick his head round the door, make sure that dad was all right and go home feeling relaxed. In terms of its furnishings, the home was a bit shabby, but they absolutely made sure that the family still felt that it was their family member, and they were just there to do the things that we were not able to do any more.

[195] **Dr Tope:** Good places also help to re-establish bonds. There are times when people are at the end of their tether; certainly, people are not always blissfully happy together, and sometimes they probably cannot stand each other. I have had evidence of that—people are about to divorce, and then one or the other gets a life-limiting illness, and the partner feels too guilty to say, ‘Well, I couldn’t stand you before, and we were just about to go our separate ways’, and so they stay. There are a number of tensions that can arise in that, and

consequently, by choosing an appropriate, good residential setting, the bond can be re-established up to a point, because visiting once a week is much easier for those sorts of families than it is having someone under your feet all day and every day. It can be a very good thing in certain circumstances.

[196] **William Graham:** May I ask you again about your experience of the information available to people? I am thinking not only of the person that needs the service, but the family. The hospital might be there for crisis intervention, but if things are getting a bit better and the person concerned can leave hospital, to go home or to a care home, the availability of information seems extremely poor. How can that be remedied?

[197] **Ms Williamson:** Unfortunately, I honestly do not know how. When an older person is in a hospital setting, that is very much the trigger for moving out of their own home into a residential setting. I suppose it would be very difficult, apart from saying, 'Go to social services', and then, unless it is an absolute crisis, you might get the transition organised. However, in terms of what you need to think about regarding the home, nine times out of 10 it will boil down to where there is a bed. It is not a real decision. I suppose that that is one of the things that we have to get better at, because I think that everybody, but carers in particular, probably have an element of denial about that. You might have a situation that was very clear—for example, if you have a degenerative disease—and there would come a point where you probably could not manage, and sometimes other people think, 'If we just try a bit harder we will be able to sustain mum or dad or my sister at home', without actually accepting or realising how wearing and tiring it is.

[198] So, we need to think about how we get information to people before they reach crisis point, so that they can actually think, 'It is not necessarily a failure if you can no longer sustain somebody at home'. Families are so complex now. Twenty-five years ago, I worked in the Rhymney valley, where there were still communities where brothers and sisters lived within 5 miles of an elderly parent. That is very different to having one son in Australia, a daughter in America, and a second marriage with step-children. People are living such complicated lives that they have to understand—and most people do—that, despite doing their absolute best to sustain people at home, there comes a point when it is not sustainable.

[199] How do we get people to think about it when they are in their 60s, and their parents are starting to get frail? Yes, they will get the support that they need to maintain them at home, if that is what they wish, but equally, they need to recognise that the chances are that they will have a fall, or a serious infection, or will get dementia. We need to be thinking much sooner about how to plan for that stage of life. We plan for retirement, and so on. When you are about to have a child, people tell you that you will need this, that and the other, and there are health visitors to tell you about the stages that you can expect with a small child, but we do not tend to do that with people at the start of the caring journey, by saying 'You may be able to sustain this for the next 10 years, but it may not be forever'.

[200] **Dr Tope:** I would like very much to see the concept of the family support worker extended. Someone made a comment earlier about residential care and nursing home care. I did my PhD in integrated care, as it happens, so I have been a convert for many years. One of my biggest concerns is the revolving door policy. When people have to move out of their home, with all the heartbreak that that causes, it seems to me that they should move just the once to where they can receive a continuum of care right through to the end of their journey. There will always be exceptions to the rule, but you should not be moving from a residential home to a nursing home to a hospital, back to a nursing home to a residential home and then for the whole thing to start all over again. To me, that is not treating people as individuals: the service user in particular, but also the family members. You want to know, trust and have a relationship with the staff and know that your loved one is loved by them. It should not be, 'That was nice, you've been here a couple of months, now you're going somewhere else',

because, particularly in the field of dementia, we know evidentially what the outcome of that is: people tend to deteriorate quickly, but they also experience distress on the day and for several weeks afterwards. The model would be to link someone, who does not have to be a nurse or a social worker, but who can be the conductor of the orchestra and who will know about pulling in the expert social worker, the occupational therapist, the nurse or whatever you need. That person would work with the family—as they do with children through their early years and Sure Start and so on—go on that journey with them and know who to pull in when necessary and they would be able to help to select the appropriate home, but with this residential-nursing home continuum.

[201] **Mark Drakeford:** Thank you for coming back to that point, because it has been a bit of a theme throughout the whole morning. It has usefully rounded off what has been a very useful session for us. Thank you both very much for coming along and helping us with the inquiry. If, at the end of the morning, you think that there are points that have not emerged strongly enough or that your members would be keen to us to bear in mind by all means let us know what they would be.

[202] **Dr Tope:** May I ask—somebody asked me this question on the phone last night, and I did not know the answer, but I would like to pose it to you, because you will be better able to find out than me—how come an elderly mentally ill registered home can charge £140 per week more than an ordinary residential home when it does not have a registered mental nurse or any specialist input of note for people with dementia? What are the criteria? There is evidence that this is happening, so people are paying £140 extra a week. I wanted to raise that, and I promised that I would, because it is a critical point.

[203] **Darren Millar:** It was a useful point to make, because we had evidence earlier this morning from—I cannot remember the name of the organisation, it was not Age Concern, but Pensioners Forum Wales, which said that it would like clearer information for people on how the fees are broken down so that they could have confidence that the fees are fair.

[204] **Dr Tope:** The person who spoke to me last night said that they are prepared to pay it, as they want the very best, but they want to know what they are getting that is different.

[205] **Mark Drakeford:** Absolutely. Thank you very much for that and for being with us today.

12.00 p.m.

Papurau i'w Nodi Papers to Note

[206] **Mark Drakeford:** We have a series of papers to note. You will see that there is correspondence from the Minister following the scrutiny session and there is more to come from her. We have formally received the paper that was circulated last week from Professor Bolton. I have two suggestions on the petitions that have been referred to us by the Petitions Committee. The Petitions Committee has decided to hold a day of oral evidence on the paediatric neuro-rehabilitation services petition, so it seems sensible for us to allow it to do that, and then we can see whether there is anything further that it wants us to do. On the petition on ambulance services in Monmouth, the Petitions Committee, as well as writing to us, has written to the Minister and to the Welsh Ambulance Services NHS Trust asking for further information. Those replies have yet to be received.

[207] **Darren Millar:** As a point of information, the Petitions Committee also wrote to me, as Chair of the Public Accounts Committee, on this issue, and we have written to the Auditor General for Wales to ask him to consider this issue as part of his future work programme.

[208] **Mark Drakeford:** Thank you for that information. It makes sense for us to be co-ordinated in these things. So, at this point, we need to wait for that extra information to come in, and we will return to the issue when we have received it. Thank you all very much.

[209] Next week, we have a whole-day inquiry in relation to wheelchair services.

[210] **William Graham:** As part of our evidence, Chair, could Members receive a copy of the commission on improving dignity in care's report that has been released overnight?

[211] **Mark Drakeford:** Yes, it would be useful for us to have that report. Thank you. Diolch yn fawr.

*Daeth y cyfarfod i ben am 12.01 p.m.
The meeting ended at 12.01 p.m.*