



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

**Pwyllgor Deddfwriaeth Rhif 5
Legislation Committee No. 5**

**Dydd Mercher, 17 Mawrth 2010
Wednesday, 17 March 2010**

Cynnwys
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Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynndi 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

Eleanor Burnham	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats
Alun Davies	Llafur Labour
Andrew Davies	Llafur Labour
Mark Isherwood	Ceidwadwyr Cymreig (Cadeirydd y Pwyllgor) Welsh Conservatives (Committee Chair)
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Leanne Wood	Plaid Cymru The Party of Wales

Eraill yn bresennol
Others in attendance

Richard Andrews	Barnardo's Cymru Barnardo's Cymru
Robert Gatis	Cyfarwyddwr y Gwasanaeth dros Ofal Cymuned, Rhondda Cynon Taf Service Director for Community Care, Rhondda Cynon Taf
Ruth Marks	Comisiynydd Pobl Hŷn Cymru Commissioner for Older People in Wales
Muz Ramzan	Gofalwyr Ifanc Barnardo's Barnardo's Young Carers
Hannah Spokes	Gofalwyr Ifanc Barnardo's Barnardo's Young Carers
Alun Thomas	Pennaeth Adolygu, Archwilio a Pholisi, Comisiwn Pobl Hŷn Cymru Head of Review, Examinations and Policy, Office of the Commissioner for Older People in Wales
Moyna Wilkinson	ADSS Cymru Arweinydd Polisi ar y Cyd i Bobl Hŷn sydd ag Anabledd Corfforol neu Nam ar eu Synhwyrâu a Chyswllt Iechyd; a Chyfarwyddwr Corfforaethol Gwasanaethau Cymdeithasol a Thai Cyngor Sir Fynwy ADSS Cymru Joint Policy Lead for Older People Physical and Sensory Impairment and Health Interface; and Corporate Director, Social and Housing Services Monmouthshire County Council

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

Stephen Boyce	Gwasanaeth Ymchwil yr Aelodau Members' Research Service
Bethan Davies	Clerc Clerk
Leanne Hatcher	Deputy Clerc Dirprwy Glerc
Bethan Roberts	Cynghorydd Cyfreithiol Legal Adviser

*Dechreuodd y cyfarfod am 9.03 a.m.
The meeting began at 9.03 a.m.*

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

[1] **Mark Isherwood:** Bore da. No apologies for absence have been received, although we have had a note from Darren Millar to say that he will be slightly late. We believe that he will be with us in around 20 minutes' time.

[2] I remind Members and witnesses that, in the event of a fire alarm sounding, you should leave the room by the marked exits and follow instructions from the ushers and staff. Please switch off all mobile phones, pagers and BlackBerrys, because they interfere with the broadcasting equipment.

[3] The National Assembly for Wales operates through the media of Welsh and English. Headphones are provided, through which instantaneous translation may be received on channel 1. Channel 0 may be used to amplify the sound, particularly for those who—like me—are hard of hearing.

[4] Please do not touch any of the buttons on the microphones as that could disable the system. Please ensure that the red light is showing before you speak.

9.04 a.m.

Mesur Arfaethedig Ynghylch Strategaethau ar gyfer Gofalwyr (Cymru)— Cyfnod 1: Sesiwn Dystiolaeth 5 Proposed Carers Strategies (Wales) Measure—Stage 1: Evidence Session 5

[5] **Mark Isherwood:** The purpose of today's meeting is to take further oral evidence in connection with the Proposed Carers Strategies (Wales) Measure. This is the fifth session to inform the work of the committee. We will be taking evidence this morning from the Commissioner for Older People in Wales and the Association of Directors of Social Services Cymru, followed by young carers. We therefore have three witnesses with us today and many questions to get through. I remind Members and witnesses that time is limited and that it would be appreciated if you could be as concise as possible with your questions and answers.

[6] I welcome the Commissioner for Older People in Wales and her colleague, and I ask them to introduce themselves for the record.

[7] **Ms Marks:** Bore da. I am Ruth Marks and I am the Commissioner for Older People in Wales.

[8] **Mr Thomas:** I am Alun Thomas, and I am head of review, examinations and policy for the Office of the Commissioner for Older People in Wales.

[9] **Mark Isherwood:** Welcome, Ruth and Alun. I will start with the first question for the morning. Is there a need for this proposed Measure and do you support its overall aims?

[10] **Ms Marks:** To explain at the outset, I will be answering quite a few of the questions and giving evidence directly from older carers. Alun will answer the questions of a more

technical nature relating to the proposed Measure.

[11] In relation to the first question, ‘yes’ is the succinct answer. To give you a bit more detail, older people and older carers tell me that they need good information and advice in a timely manner and in a format that is accessible to them. They also want to make sure that they are involved, so that their voices are heard in relation to services and policies that affect them and those that they care for. The proposed Measure represents to older carers an important staging post in the development of establishing duties on public authorities so that carers can be more easily identified and be informed and advised so that they can exercise their rights.

[12] The importance of providing streamlined and simplified advice and information in a timely manner has been a major theme in many of the meetings that I have been involved with all over Wales and also in written evidence that is sent to the commission regularly. The commission is particularly concerned with the issues in relation to older carers, and therefore supports this proposed Measure. Over half the carers in Wales are older people. A fifth of older people in Wales have caring responsibilities, with a third of those undertaking care for 50 hours or more a week. A fifth of older carers report that they are in poor health, which makes the link with health organisations relevant, and that rises to a third of people aged 85 and above. These statistics are important, particularly given the demographic trends and the prospective increase in demand. The demand is set to increase by 40 per cent over the next 10 to 12 years.

[13] The commission believes that the proposed Measure imposes relevant duties on public authorities to draw up carers strategies, which builds on the requirements already in place and those that are forthcoming for many of those who are cared for. Unlike other equality schemes and strategies, this proposed Measure will require public authorities to work together formally on joint strategies. That is groundbreaking in Wales and should be congratulated. It also gives an example for others to follow.

[14] **Leanne Wood:** Given what you have just said, can I take it that you do not think that the aims of this proposed Measure can be met through existing legislation?

[15] **Ms Marks:** No, we do not. It is our opinion that the proposed Measure is needed and will be helpful. Alun will provide you with some technical detail on that question.

[16] **Mr Thomas:** Consolidation, for example, is a good thing, but we must remember that the existing three pieces of legislation in relation to carers, particularly the Carers (Equal Opportunities) Act 2004, have not been implemented effectively and coherently in Wales. We also need to consider the broader issues around rights and duties in relation to carers because there are two distinct approaches. Most of the rights-based approaches will probably be best addressed through the UK context and, in particular, through the Equality Bill that is in the last stages of consideration in the House of Lords. What we know about the Equality Bill is that discrimination by association will be recognised for the first time in relation to employment and access to goods and services, but only from the perspective of those people who are caring for disabled people, not for people who are caring for older people but not necessarily covered by disability discrimination definitions, and not for children in their own right, for example.

9.10 a.m.

[17] The rights-based approach has limitations at the moment, so we would not necessarily be consolidating from the point of view of strength. We need an approach that looks at imposing duties as well as enshrining rights because many older people in particular are not in a position to exercise their rights. Many people are fighting their own battles over long

periods, and the last thing that they want to have to deal with in order to obtain redress is a cumbersome piece of equalities legislation. In that sense, we are still waiting for the Ministry of Justice to take action in relation to group or class actions to enable people to take representative actions to enshrine and enable people's rights. Therefore, a duties approach, as set out in the proposed Measure, will be very important to complement the rights-based approach and fill in the gaps.

[18] **Leanne Wood:** Are you saying that the rights-based approach and the duties that will come from the proposed Measure will go hand in hand and work together? Given what you have just said about the limitations on duties in the UK equalities legislation, how will the proposed Measure plug the gaps left by those limitations for young carers, to use an example that you gave?

[19] **Mr Thomas:** Taking a duties-based approach mirrors some of the approaches taken with regard to imposing equality duties on public authorities. There are duties in relation to race, gender and disability at the moment, and those will be extended to age. We think that the new duties will come into effect in April 2011, general election and so on permitting. However, there is no specific provision to impose equality duties in relation to carers across the piece. So, generally speaking, rights-based legislation is enabling people who have been discriminated against to be protected, rather than protecting those associated with that individual. There is a gap, particularly in relation to the public duties, although the gap in relation to goods and services will be plugged.

[20] **Leanne Wood:** Do you therefore think that the proposed Measure should include the right for carers to access information, the right to be consulted and so on?

[21] **Mr Thomas:** One of the things that is critical here is that we have effective strategies, particularly for older carers, who come under our remit, to ensure that they are specifically involved at all stages. We think that there would then be extra recognition and advice and information provided to carers so that they could make informed choices on how to take things forward, rather than having to go down the same route as Sharon Coleman, who had her legal case taken to the European level to establish that she had a right, as a carer for a disabled child, to have more flexible working arrangements with the legal firm that employed her at the time. That cannot be the right route for every carer, given the demands of caring.

[22] **Leanne Wood:** Thank you for your answers. In the evidence paper you provided for the committee, you express concern that the strategy process can become an end in itself. You cite the example of the Disability Discrimination Act 2005, which included this unequivocal statement on duties, outcomes and user involvements. What lessons can we learn from this? How could the proposed Measure address the concerns that you have outlined there?

[23] **Ms Marks:** I will start on this and then I will hand over to Alun to talk about his experience from disability equality work. I am sure that a typical comment that you are familiar with hearing from people across society in Wales, but particularly from older people, is that there seems to be far too much red tape, and the systems, despite good intentions, seem to conspire against things, and people can fall through the cracks in the pavement. The proposed Measure is an opportunity to fulfil that duty to provide information and advice.

[24] If health organisations work with local authorities, which already have carers strategies, there is no reason why the development of a strategy, which could potentially be led by the health service, cannot work. When the health service and local authorities do not work together, older carers, older people and people generally fall between two camps. That is what people want to put right through using the fullest amount of common sense. Older people have expressed real concern to me, verbally and in written evidence to the commission, that good intentions and seemingly watertight policies are not translated into consistent practices

when services are delivered. However, heavy weather does not need to be made of this; there are already carers strategies within local authority frameworks, and a strategy does not need to be an all-embracing, huge piece of work that takes up huge amounts of resource and so on. The health service and local authorities can work together, and they can work in partnership with other organisations in the third or voluntary sector and in the private sector. A general sense of collaboration and signposting towards good information and advice will help a great deal. I will pass back to Alun for a bit more detail on that.

[25] **Mr Thomas:** To give a little bit of history in respect of the Race Relations (Amendment) Act 2000 and the requirement in that Act for public authorities to bring forward race equality statements, there was some criticism of that, and in particular of the fact that there was too much of a focus on process and that it was too much of a tick-box exercise. People learned from that in relation to bringing forward gender equality duties and disability equality duties.

[26] In relation to disability equality duties in particular, the approach that was taken was to set out six specific areas on the face of the Disability Discrimination Act 2005 that the disability equality duty would cover. The approach in the proposed Measure is slightly different in respect of setting out what regulations might include. Regulations were equally important in relation to the disability equality duty, and they stated specifically that disabled people should be involved at all stages of the disability equality scheme. They did not necessarily have to be consulted—and there is an important distinction, which we might dwell on later. As a consequence, the schemes themselves had to stipulate outcomes as well as the process and outputs. That is an important distinction. These strategies need to open the door to meaningful change that will transform the lives of individual carers.

[27] In the context of the disability equality duty, we saw some really creative thinking across local authority and health boundaries, and I am pleased to say that Wales was at the forefront of that—and health authorities and local authorities in north Wales in particular. I addressed meetings in Conwy and Denbighshire where local authorities and the health service came together. Research that was done at a UK level commended the particular approach taken according to economies of scale in local authorities and health authorities in north Wales. People were involved at all stages, and outcomes were based on that involvement, particularly in respect of identifying the right priorities on the basis of what people were saying.

[28] **Leanne Wood:** It sounds as if you are saying that you are placing quite a lot of faith in the carers strategies; however, they will not be legally binding. You mentioned earlier the problems regarding the lack of implementation in relation to existing legislation. What if these strategies are not implemented? What if the health service does not work with social services?

[29] **Mr Thomas:** There has to be effective redress. The strategies will have to be presented to the Deputy Minister, who has the option of not allowing them to be continued if she is dissatisfied with their content.

9.20 a.m.

[30] However, there needs to be a degree of answerability to carers, which brings us back to involvement rather than consultation. We must not see consultation as a rubber-stamping exercise. We know that the Deputy Minister has made some positive comments along these lines. It is helpful to have comments to clarify the intent of the law at different stages. We need a combination of a clear Measure, clear regulations and ministerial statements at different stages to help us through this, so, if there is confusion, we can return to the Record and see what the Deputy Minister has said with regard to establishing intent.

[31] **Leanne Wood:** Thank you for that. Section 2 of the proposed Measure imposes a duty to produce a carers strategy on NHS bodies as well as local authorities. You have said that you agree that there is a need to impose a duty on NHS bodies. Can you tell us why you have said that, please?

[32] **Ms Marks:** I would like to highlight two reasons. First, interaction with health services is often the first means of identifying that someone is a carer. As Alun has already said, many older people may resist the label of ‘carer’, but they may be more likely to see the benefits of identification if the issue was raised sensitively by a health professional in whatever setting. Certainly, doctors are the first point of contact for most carers.

[33] The second reason is that health providers are generally acknowledged to be underperforming in recognising and addressing the needs of carers. I believe that that has already been stated in evidence given both by the neurological alliance and the carers alliance. There are some particular areas of sensitivity where both those who are cared for and the carer may need to be furnished with information; for example, around the application of treatments, or particular medication or changes to medication.

[34] I would also like to mention that there has been innovative practice already to link GP surgeries with referrals to citizens advice bureaux across Wales. We also know that there have been good partnerships between the organisation and the local services of Care and Repair Cymru and GP surgeries. The status and contractual position of GPs would need to be taken into consideration if more is to be expected of them in terms of broaching caring responsibilities sensitively. However, once again, it comes back to the point that we do not necessarily need to make heavy weather of this. An awful lot of information and advice provision can be a matter of correct signposting. If you do not know the answer yourself, or you are not the agency responsible, all you need to do is to be able to refer that person to someone who will know. The more direct we can make that route, the better it will be for people.

[35] **Leanne Wood:** Are you satisfied that, as drafted, duties on NHS bodies in the proposed Measure will help to ensure that those carers are identified within the health service and that general practice with carers is improved in health?

[36] **Ms Marks:** Yes, with the proviso that there will be increased collaboration and close working across local government and health.

[37] **Leanne Wood:** Thank you very much for your answers.

[38] **Alun Davies:** I was interested in one of your earlier remarks about red tape. You said that it seemed to be an impediment in that structures—and I think that you used the term ‘bureaucracy’—can sometimes impede people’s ability to receive the services that they require. I am not clear as to why you think the proposed Measure will address those issues.

[39] **Ms Marks:** That is a good question. The proposed Measure, as it is designed, sets that overall principle of the importance of working together. I do not think that the strategy needs to be an end in itself, which relates to one of the questions that Leanne asked earlier. If local authorities and health services work effectively together and share the information that they already have on carers strategies and develop a protocol, or a method of working that improves information, advice and signposting, then I do not think that that needs to equal more red tape. Ultimately, if carers are involved in the development of that work, they will say, ‘Actually, the most direct route to get me the information that I am looking for is this way’. If the people who are making policies and delivering services listen to carers’ voices and experiences, red tape is likely to be reduced. Alun wants to add something, so I will pass

over to him.

[40] **Mr Thomas:** Effective involvement is the key. We know from survey work that has been done by Carers UK that 58 per cent of the carers that it interviewed did not claim benefits to which they were entitled for three years and that 65 per cent of carers do not identify themselves as carers in the first year of caring, because caring, for many people, is an evolving process. Trying to involve people effectively, in a non-threatening way—I am afraid that, particularly in relation to older people, there is stigmatisation in relation to social services involvement, and I am sure that we will come on to health as the lead organisation in a moment—as has been achieved in relation to disability equality discussions, will give people a much clearer awareness of their rights. However, if the strategies are done as a tick-box exercise and stay on shelves, never to be challenged, one has to ask a serious question about their intent. We can determine what intent is here and in regulations.

[41] **Alun Davies:** Much of what you have said has been the policy of the Government for many years—the whole collaboration agenda. The Government has been pushing public service delivery bodies to work together for some time. This will now give a statutory basis for some of the strategies, but the key issue, as I see it, is not the strategies but, as Mr Thomas alluded to in his final answer, the implementation. Implementation is key to this, and I am still not entirely comfortable that the proposed Measure will deliver an implementation framework that will deliver rights. Your written evidence has a slightly different tone to what you have said this morning on rights. You are a lot more in favour of rights in your written evidence than you have been in your oral evidence this morning, but we will let that go for the moment. Imposing duties on public bodies still does not deliver the services to people that we all want to see.

[42] **Mr Thomas:** Our concern with a rights-based approach is that it is a case of he or she who shouts the loudest gets the services. That has certainly been my experience of how you contact people who are busily undertaking caring. I am thinking of the case of a couple that we came across where one person aged 78 with mental health problems was caring for a person aged 81 with physical problems. How are we going to change the lives of those people significantly unless we take the duties-based approach to supplement the rights-based approach? We need both. There are still steps, as I indicated, that we would anticipate the UK Government taking in relation to enshrining greater rights for carers, not least in ensuring that people are getting the financial support that they need. That is a particular problem for people who are embarking on older age, that is, across pensionable age, considering the impact that funding changes would have on them.

[43] **Mark Isherwood:** I advise Members that we only have 20 minutes with these witnesses. We will go five minutes over schedule because of our late start, but I ask you to be as concise as possible, because there are still a lot of questions to ask.

[44] **Andrew Davies:** I would like to follow up the question that Alun asked. I do not think that we disagree with the ultimate policy objective, which is better services through the involvement of carers and those who use services. However, to play devil's advocate, is taking a legislative approach the right way to tackle this? You quote the Disability Discrimination Act 2005 in your evidence, and I have seen several examples of where public bodies—local authorities, health boards and others—have adopted a tick-box approach. Even though there is a statutory duty, the point that Alun was making is that behaviour has not changed.

9.30 a.m.

[45] You may argue that putting things on a statutory basis is a necessary if not sufficient approach, but, like Alun, I am still not sure whether a legislative approach will give you the

outcome that you desire.

[46] **Mr Thomas:** I think that we need several tools in the toolbox, which is critical. This is only one tool albeit an important one, but the way that it is shaped and carried through will be very important. I think that Ruth wants to comment.

[47] **Ms Marks:** I think that carers have been off the agenda, or off the radar, in terms of a whole range of policies and services for a very long time. Given the combination of increased demand and changes in demography, this particular tool in the toolbox that Alun mentioned will be a very useful one.

[48] **Mark Isherwood:** Effective change needs to be managed, as well as imposed statutorily. I now call on Darren.

[49] **Darren Millar:** I apologise for arriving late this morning. One of the peculiar things that the committee has tried to do is understand why the Deputy Minister wants the opportunity to be able to designate a NHS body as the lead body in terms of the development of carers strategies. We all know that it tends to be local authorities that have the longer and more established links with carers, and tend to be providing support. You say that you support the opportunity for the NHS to take the lead. Can you tell us a little bit more about why you support the NHS being a lead body rather than local authorities?

[50] **Mr Thomas:** The first point, from our perspective, is that there needs to be a lead authority. This is particularly an issue in relation to joint working and joint programmes. Sometimes, the focus is lost in relation to who leads in terms of equality responsibilities, for example. We certainly support having a lead authority, and we acknowledge the good work that has been done in relation to local authorities in establishing fora. As has been said, health is lagging behind, but one of the key attractions for us in having health bodies as lead bodies is that, hopefully, we will have fewer strategies. That would make it more manageable for the Deputy Minister in her role in terms of reviewing the strategies. It seems to us that it will be significantly more effective to localise streams to represent local authority boundaries within a broader regional strategy, than to take 22 strategies and try to pick from them regional trends. Therefore, that is significant in itself.

[51] It is important to embed, within the leadership of health bodies, the importance of this work in relation to carers. It has been a neglected area in relation to health. Also, the health service is the first point of contact for significant numbers of older carers, particularly access to GPs. You have heard already about the prevalence, particularly among older carers, of poor health. Therefore, health is an important gateway to identify people who may be stigmatised and fear approaching social services on the very basis that the management, care and love that they provide might be undermined, in their view, by identifying themselves to social services in the first instance.

[52] **Darren Millar:** Do you think that there are any circumstances where it would be appropriate for a local authority to take the lead, or are you convinced that health should always take the lead in the development of these strategies?

[53] **Ms Marks:** If the partnerships are developed appropriately, there might be opportunities for other organisations to take leads in due course. However, if the proposed Measure flows through and health has the lead and there is a focus on aspects around health, social services and housing in the first place, for instance, those partnerships with local authorities should automatically flow. In terms of the lead, the answer is 'yes', but in terms of making it happen, I do not think that it will cause too many problems.

[54] **Darren Millar:** Given that some local authorities have got it right and are doing a good

job on this front already, is there a risk that that could be jeopardised by the NHS suddenly taking the lead from the local authorities that have been doing the job well?

[55] **Ms Marks:** I do not see any reason for that. The local authorities that have good practice in place will want to share it, and carers who are accessing good support will want to ensure that it continues. If carers are involved in this process, and if their experiences and so on are listened to effectively, good practice should not be lost. Local authorities will want that to happen and the health service will not want to reinvent the wheel.

[56] **Darren Millar:** You mentioned that there are now fewer health bodies than there are local authorities. Given that there are fewer health bodies, is there a risk of there being a generic strategy and delivery across a whole local health board area, if we are not careful—and I think that you described it, Mr Thomas, as an ‘overarching strategy with local delivery’?

[57] **Ms Marks:** The lack of coterminous boundaries could, in some ways, be helpful. It will help local authorities, some of which serve small populations, to think strategically and to work with other local authorities as well as health organisations. It will also encourage health authorities to think about how the strategy can be tailored and delivered at a local level, as you mentioned. Our main motivation for suggesting that health services take the lead authority role in this is so that the number of strategies can be reduced, and so that they can be overarching, as Alun said. Reference can be made to the good and innovative work that the strategy for older people in Wales has developed in local authorities. The Welsh Local Government Association and strategy co-ordinators at a local level are already making links with colleagues in the health service to deal with issues affecting older people, many of whom are also carers. People will not want to lose that good practice and reinvent the wheel. Those lessons should be learned and should be easily transferred.

[58] **Alun Davies:** You used the word ‘involvement’ in one of your earlier answers, but the proposed Measure uses the word ‘consultation’. They are two different words with different meanings. How do you believe the proposed Measure delivers the involvement that you seek?

[59] **Mr Thomas:** There are potential difficulties on that. We are particularly pleased that the Deputy Minister has gone out of her way to say that consultation should be more than a rubber-stamping exercise. We understand that the regulations can be used appropriately to explain what consultation means in practice and what the expectations are. However, in my experience, it is better to make it clear that involvement is required at all stages, so that consultation does not occur only when the strategy has been well defined. That also addresses the potential difficulty that there is no provision to go back to carers to explain what has been done, or to involve carers in evaluation and in reporting once the strategy has been developed. That is a weakness.

[60] **Alun Davies:** What the Deputy Minister says is one thing, but what is in law is another. We can rely on regulation, but we have not seen any yet. What we have in front of us is the proposed Measure. I do not think that you have answered my next question in your written evidence. Do you believe that the proposed Measure as it stands provides you with the certainty that the sort of involvement that you seek will be delivered? You have been quite negative this morning when talking about past strategies, and you have said that they have not worked. I do not believe for a moment that previous Ministers acted with any lack of good faith in this matter. To return to a more recent point, implementation failed the policy objectives. Where do you see the rock-solid guarantee in this proposed Measure that gives you the certainty that we all seek?

9.40 a.m.

[61] **Mr Thomas:** Three things are needed. There could be a change in the wording of the

proposed Measure to relay the fact that involvement, rather than consultation, is important and should happen at all stages, not just at that stage stipulated in the proposed Measure. Ministerial statements are important because, if there is any element of doubt, what a Minister has said on the record can be used to best effect. So, the careful use of ministerial words is important in that context. Of course, the regulations are also important. As it stands, I am bound to say that there are questions relating to using the affirmative rather than the negative procedure. So much detail is needed at the moment that we would probably favour going down the affirmative route. However, if there were a few more details on the face of the proposed Measure, perhaps the negative route could be used more effectively. Apologies if I have jumped the gun on one of your future questions.

[62] **Mark Isherwood:** Time being tight, we are grateful for that.

[63] **Andrew Davies:** On that last point, presumably, there was early consultation on this piece of legislation. I have some sympathy with your strong view on the use of the words ‘involvement’ or ‘engagement’ rather than ‘consultation’, but what was the response of officials to that?

[64] **Mr Thomas:** We have given evidence about the LCO, but this is the first involvement that we, as the office of the older people’s commission, have had with the proposed Measure.

[65] **Andrew Davies:** However, you made some points at an earlier stage. What was the argument for sticking with ‘consultation’ rather than ‘involvement’?

[66] **Ms Marks:** I do not have the detail on that, Andrew, I am sorry. We can check and get back to you.

[67] **Alun Davies:** Before we leave that matter—[*Inaudible.*]—could we have a note from the committee secretariat, perhaps, to outline the discussions held by the previous committee on these matters, because they are important?

[68] **Ms Marks:** We will certainly check any information that we have at the commission that might be relevant and feed that through to colleagues.

[69] **Eleanor Burnham:** Hoffwn ofyn cwestiynau am wybodaeth a chyngor addas, fel y bu ichi eu trafod. Bu fy mam yn gofalu am fy nhad nes ei bod hi yn ei 80au, felly yr wyf yn cydymdeimlo’n fawr â’r dystiolaeth yr ydych wedi ei rhoi inni y bore yma.

Eleanor Burnham: I would like to ask a question on appropriate information and advice. My mother cared for my father until she was in her 80s, so I have great sympathy with the evidence that you have given us this morning.

[70] Mae adran 3 o’r Mesur arfaethedig yn diffinio gwybodaeth a chyngor priodol. A yw hwnnw’n ddiffiniad boddhaol? Ar hyn o bryd, mae popeth ar gael ar y we sy’n golygu, yn fy marn i, nad oes modd i nifer o bobl gael mynediad i’r wybodaeth briodol ac amserol, fel y bu ichi ei drafod yn gynharach.

Section 3 of the proposed Measure defines appropriate information and advice. Is that definition satisfactory? At the moment, everything is made available online, which means that, in my opinion, many people cannot access appropriate and timely information, as you discussed earlier.

[71] **Mr Thomas:** Cyfeiriaf yn gyntaf at eich pwynt ynghylch y we, ac mae’n berffaith gywir dweud hynny. Mae gan ryw 29 y cant o bobl hŷn fynediad i gyfrifiaduron yn eu cartref o gymharu â’r cyfartaledd o ryw 59 y cant, hyd y deallaf. Felly, mae hwnnw’n

Mr Thomas: I will first address your point on the internet, and it is perfectly correct to say that. Around 29 per cent of older people have access to computers at home, compared with the average of around 59 per cent, I understand. So, that is a factor and we must

ffactor a rhaid sicrhau bod y wybodaeth yn cael ei darparu mewn sawl ffordd. Fodd bynnag, o'n safbwynt ni, un peth sy'n ysgytwol yw cyn lleied o wybodaeth sydd ar gael i bobl am y cyllid, gan gynnwys budd-daliadau a threth. Yr wyf eisoes wedi cyfeirio at ffigurau i ddangos na chafodd 58 y cant o'r gofalwyr a holwyd gan Carers UK unrhyw wybodaeth am fudd-daliadau yn ystod y tair blynedd cyntaf o ofalu. Hoffwn sicrhau nad yw'r gwaith a wneir o fewn y strategaethau yn cadarnhau y ffiniau unigol rhwng yr hyn a ddatganolwyd a'r hyn sy'n gyfrifoldeb i San Steffan, oherwydd mae'r holl fater o gyllid yn bwysig, yn arbennig i bobl hŷn. Gwyddom fod pobl sy'n derbyn gofal yn wynebu gwahaniaethu yn y system budd-daliadau pan maent yn cyrraedd 65 oed. Mae cymhwysedd y lwfans byw anabledd yn llawer mwy cwmpasog nad ydyw i'r lwfans gweini.

[72] Gwyddom hefyd fod pensiynau galwedigaethol a phensiynau gwlad yn effeithio ar gost gofalu. Mae'n allweddol bod yr wybodaeth hon, sy'n cael ei darparu gan y trydydd sector yn amlach na pheidio, yn cael ei ffactora i mewn i'r strategaethau hyn.

[73] **Eleanor Burnham:** Sut y dylai hynny ddigwydd? Yr ydych yn sôn am ddarparu'r wybodaeth hon. A ddylem gynnwys rhywbeth yn y Mesur arfaethedig ynghylch lle y dylai'r wybodaeth fod ar gael? Er enghraifft, gwyddom nad yw llawer o bobl yng nghefn gwlad yn gallu mynd i swyddfeydd gwych Cyngor ar Bopeth. Mae'r swyddfeydd yn rhoi gwybodaeth wych, ond nid ydynt ar gael i bobl. Felly, a ddylem roi rhywbeth yn y Mesur arfaethedig am hynny?

[74] **Mr Thomas:** Mae cwestiwn yn codi ynghylch blaenoriaethu gwasanaethau cymdeithasol a thai. Byddwn eisiau sicrhau—yn y rheoliadau, efallai, gan eu bod yn fwy perthnasol—ein bod yn edrych ar wasanaethau o ran budd-daliadau lles. Mae nifer o awdurdodau lleol yn cynnig y wybodaeth honno neu'n ei phwrcasu gan y trydydd sector. Mae'n bwysig bod y rheoliadau'n adlewyrchu hynny.

[75] **Ms Marks:** I just want to make sure that colleagues are aware of a partnership that the Department for Work and Pensions and the Pension Service have with the Welsh Assembly

ensure that the information is provided in many ways. However, from our point of view, one thing that is shocking is how little information is available to people about funding, including benefits and tax. I have already referred to the figures that show that 58 per cent of the carers who were questioned by Carers UK were not given information about benefits during their first three years of caring. I want to ensure that the work that is done within the strategies does not reinforce the individual boundaries between what is devolved and what is the responsibility of Westminster, because the whole issue of funding is important, particularly for older people. We know that people who are cared for face discrimination in the benefits system when they reach the age of 65. Eligibility for the disability living allowance is far more open than for the attendance allowance.

We also know that occupational pensions and state pensions have an impact on the cost of caring. It is crucially important that this information, which is most often provided by the third sector, is factored into these strategies.

Eleanor Burnham: How should that happen? You mention providing this information. Should we include something in the proposed Measure about where that information should be provided? For example, we know that many people in rural areas are unable to access the excellent bureaux of Citizens' Advice. They provide excellent information, but people cannot access them. So, do you think that we should include something in the proposed Measure to that end?

Mr Thomas: A question then arises regarding the prioritisation of social services and housing. I would want to ensure—in the regulations perhaps, given that they are more relevant—that we look at services relating to welfare benefits. A number of local authorities offer that sort of information or procure it from the third sector. It is important for the regulations to reflect that.

Government and local authorities, building on a previous programme called LinkAge Plus, which is still live, in fact. The Pension Service is working hard with the Assembly Government and local authorities around Wales to provide advice on unclaimed benefits and to make sure that people have the information that they need to claim the money to which they are fully entitled. The Assembly Government and local authorities possibly have similar examples of good practice in other portfolio areas already, and so we need to make sure that we do not lose those and that they translate across to the benefit of carers, and older carers in particular, given our interest.

[76] **Eleanor Burnham:** Do you agree that the information needs to be up to date and correct? People face an enormous amount of problems when accessing benefits. Mistakes are made—not by them—and that money is then clawed back. Surely that is a deterrent factor.

[77] **Ms Marks:** You are quite right. It is a deterrent factor. Another is the fact that the systems are so complicated. When you are offered the chance of having some time off from caring for someone, you are likely to want to go for a walk around the park or spend time with your grandchildren rather than plough through a 40-page form that may or may not be successful. That is where the support and advice of the third sector, local government or the Pension Service are really helpful.

[78] **Eleanor Burnham:** I symud ymlaen, pa mor hyderus ydych chi fod adran 3 o'r Mesur arfaethedig yn sicrhau y bydd anghenion gofalwyr hŷn yn cael eu bodloni o ran argaeledd a hygyrchedd? **Eleanor Burnham:** Moving on, how confident are you that section 3 of the proposed Measure will ensure that the needs of older carers are catered for in relation to availability and accessibility?

[79] **Ms Marks:** This is another example of the importance of the duty to work with local authorities. We refer again to the older people's strategy and the link with the third sector, pensioners' organisations and retirement associations. They all have a part to play. In practical terms, we anticipate the regulations detailing by example the sorts of activities and approaches that can reach the greatest number of carers, and doing so will involve adequate resources. For example, carers who have limited windows of opportunity to take part and to get involved might need support to get to and from meetings, and so there should be extra focus on specialist support, such as interpreting support and so on. However, I think that most people who are developing policies and services have already integrated that into their plans. The timing of intervention and the sensitivity of approach will also be important for significant numbers of older carers.

[80] **Eleanor Burnham:** Yn olaf, a oes adrannau yn y Mesur arfaethedig y credwch y gellid eu gwella neu eu hegluro'n well? **Eleanor Burnham:** Finally, are there any sections in the proposed Measure that you believe could be improved upon or clarified?

[81] **Ms Marks:** There is nothing over and above the comments that we have already made.

[82] **Mark Isherwood:** I will have to bring the questions to an end now. We have missed a few questions out, but your answers have covered such an extensive range of issues and you have answered in such a helpful way that you have answered many of them anyway. If there are any questions that we need further clarification on, we will write to you, if that is acceptable, and we would be grateful if you could provide us with your written answers as soon as practicable.

[83] **Ms Marks:** That is fine. If the notes that we have made in response to the questions would be of use to colleagues, we can make those available. That might address some of the anomalies to which some Members have alluded in relation to the differences between our written evidence and the material that we wanted to raise this morning.

9.50 a.m.

[84] **Mark Isherwood:** That would be very helpful. Thank you. Are there any other issues that you would like to raise or closing remarks that you wish to make?

[85] **Ms Marks:** No. Thank you.

[86] **Mark Isherwood:** In that case, it just remains for me to say that the clerk will forward a draft transcript of today's proceedings to you to check for accuracy before the final version is published. Thank you both for attending this morning. Have a happy day at work.

[87] **Ms Marks:** Thank you. Diolch.

[88] **Mark Isherwood:** We now have witnesses from the Association of Directors of Social Services Cymru. Good morning, welcome and thank you for joining us today. I would be grateful if you could introduce yourselves for the record.

[89] **Ms Wilkinson:** Good morning, my name is Moyna Wilkinson. I am the corporate director of social and housing services for Monmouthshire County Council. I am also one of the joint policy leads on the health and social care interface for ADSS Cymru.

[90] **Mr Gatis:** I am Bob Gatis, service director in Rhondda Cynon Taf with responsibility for adult social services in the county borough council.

[91] **Mark Isherwood:** Thank you. I advise you both that committee members may ask questions through the medium of Welsh. Should you require it, you can hear the instantaneous translation on channel 1 of the headsets. Channel 0 can be used for amplification if you are hard of hearing. I will begin the questions. Do you feel that there is a need for this proposed Measure and do you support its overall aims?

[92] **Ms Wilkinson:** Yes, we support the overall aims and we see a need for the proposed Measure. In particular, we consider the introduction of a specific duty on the NHS in relation to carers to be crucial. That is the information that carers have given us, it is the information that has come through the carers strategies and the work on carers that has already been undertaken within local authorities. We already work in strong and often productive partnerships with the NHS in relation to carers, but there are matters on which carers may not be in contact with local government or its services, such as the point when someone is diagnosed. With regard to GP surgeries, some of the interaction on health matters means that people are not known to us. Carers have fed back to us that it is vital at times that people dealing with the person being cared for know that they are there as well. There is a quotation that you may have heard before from a carer who was sitting with her husband when he was given his diagnosis: she said that it was like being dropped in the North sea and being asked to swim home. At that point she just felt completely at a loss. I do not want to criticise the very good work that has been done, but we need to do more for carers and we want to do more for carers, so we think that there is real value in a duty being placed on the NHS.

[93] **Leanne Wood:** You say in your written evidence:

[94] 'we are concerned that a Measure is being pursued to prescribe a requirement for the production of another strategy'.

[95] Given the fact that local authority strategies take information issues into account already, is there a need for further strategies, and could the aims of the proposed Measure be achieved using the existing legislative framework?

[96] **Ms Wilkinson:** As I said in my previous answer, this is an issue of duty. For most of us, it is important to think strategically and to look at where the priority needs are. I appreciate that there is sometimes a requirement for the NHS to ask where it needs to concentrate its efforts. I can see that the overall assessment of how to implement something is very important. For me, however, the key is the implementation, whether we can demonstrate that something is making a positive difference to carers on the ground. I will always say that we should concentrate on making a difference and making an improvement rather than writing strategies. It is a case of getting that balance right. I am not trying to deride strategies or say that they are not necessary as a guide or something to refer back to. However, I want the effort to be directed at assisting carers.

[97] **Leanne Wood:** Do you think that the aims of this proposed Measure could be achieved using existing legislation?

[98] **Mr Gatis:** I suspect that existing legislation is defined largely in terms of social services functions and so forth. This proposed Measure widens that far more in respect of local authorities, though, as Moyna has said, the key duty would lie with the NHS. NHS responsibilities relating to carers have not been well defined to date, and the proposed Measure would therefore be extremely helpful. I do not think that other legislation picks up the needs of carers in the way that this proposed Measure does.

[99] **Ms Wilkinson:** I will just give the example that I used when I gave evidence to a previous committee. In Monmouthshire, we have a worker located within a health setting, in GP surgeries, trying to make sure that information and support is available to carers within that setting. We have 14 practices in Monmouthshire, and the worker, Debbie, has gone into 11 of those. She has struggled to make inroads at the other three. We have tried to be persuasive, but it does not feel quite right that we have not covered all of the GP surgeries. That is not because there is a lack of support from the NHS; I do not want you to think that. However, it is important that we can point to something that says 'You have to', as opposed to 'You can choose to'. It is important enough to have to do that.

[100] **Leanne Wood:** You think that this proposed Measure would put you in a better position to ensure that those GP surgeries are involved in that.

[101] **Ms Wilkinson:** The GP surgeries are just one part of it. We are also aware that, within the acute sector in secondary care, as I mentioned in my first answer, a range of people are going to consultants, getting diagnoses and so on but who may not be known to existing services for carers.

[102] **Leanne Wood:** Okay, thank you. You state in your evidence that a change in the proposed Measure is required in relation to young carers, to make sure that they are not overlooked and fall through the cracks. Why might they be overlooked, and what changes would you propose to this proposed Measure?

[103] **Ms Wilkinson:** I do not think that it is a surprise to anyone that young carers can be missed, despite considerable effort and work to find them. It is fair to say that, within ADSS Cymru, there are differing views. We are aware that the Deputy Minister for Social Services is going to address issues relating to young carers appropriately in terms of young people's legislation. The recommendation that we would make for this proposed Measure is that it needs to mention 'young carers and carers of all ages'. This can then be further defined in the guidance provided. The main legislation is going to relate to children. However, for us, this separation is necessary because of the very different legal situation surrounding children, as well as their different needs. It is just a question of emphasis. ADSS Cymru covers children and adult services, and this is about being aware of those different sets of needs and the roles

that young carers can sometimes be placed into. That is why we wanted mention of that one. I do not think that we need to list everybody, but we appreciate that the major legislation relates to the children's legislation.

10.00 a.m.

[104] **Leanne Wood:** We have taken evidence from others that supports the view you have just put. Barnardo's Cymru suggested inserting the words 'of any age' in the proposed Measure, which would clarify the inclusion of young carers. Would you support that approach?

[105] **Mr Gatis:** I think that we would argue that the words 'of any age' would include children but that their inclusion does not place sufficient emphasis on young carers. As Moyna indicated in a previous answer, we would prefer a particular emphasis to be placed on young carers as a specific group in the proposed Measure. That would make it even clearer that we are talking about people of all ages.

[106] **Ms Wilkinson:** We appreciate the link to legislation on vulnerable children and children and families.

[107] **Darren Millar:** I want to ask you about the duty to produce strategies. You are obviously pleased that the NHS is going to be sharing this duty with you. You have already explained that there needs to be an improvement in NHS engagement. However, do you think that there will be a risk that your local delivery will be jeopardised? Could some of the good work going on in your local authorities be superseded by the health board approach, with a push for consistency across a health board area?

[108] **Ms Wilkinson:** First and foremost, I am pointing out the importance of having measures that attempt to reach carers when they need it. For me, and I think for Bob and ADSS Cymru, the carers' needs are the driver. Information that has come back to us from carers is that the strategies and the work that has been done are appreciated but that a considerable number of carers may not be contacted or may not know how to contact people for information. You want to get to them at the point when they need some assistance and support. That is our major motivation. I praise the efforts of my colleagues throughout the principality on carers strategies. There are carers' workers who work very closely with carers' groups and help to develop them. The carers strategies that exist across the principality are a record of that. We have come a long way in that work; we had to come a long way, to be quite honest. It is quite an eye-opener. The people who work with carers are a very passionate group of people. We have seen quite senior members of staff changed by their experience of working with carers. They begin to understand, and then they have a lightbulb moment when they really begin to understand exactly what some of these people are doing.

[109] Consequently, there is a concern that the good work may not be built on and that people will start afresh. That is absolutely understandable. Having said that—I can speak for my area and Bob can speak for his—the relationship with health services is good. We are aiming for collaboration, we have very strong aims with regard to integration, and I have a joint commissioning team, which I have had for years, with the local health board. So, the production of strategies has always been done jointly. Following the reorganisation, the acute sector, which is a big player in this, has been brought in. The important thing about this is to build on what we have, to increase it. We are of the view that this piece of legislation offers that opportunity. We are hoping and expecting that our NHS colleagues will be working with us because, realistically, who wants to start from scratch? In some areas it may be a case of starting from scratch in relationships with the acute sector. There is probably some more work to do in that area, but I am not speaking for the whole of Wales.

[110] **Mr Gatis:** I think that you are quite right; there is probably a difference of view across ADSS on occasions about whether this will hinder or harm. As Moyna has said, it is about working and building on what we have in terms of strategies. One of the things that the proposed Measure will seek to achieve is a greater consistency across Wales, which will be helpful. As Moyna says, we are working very closely with the NHS.

[111] **Darren Millar:** I think that that is the problem, though. You may well be working very closely with the NHS in your areas. In some areas, it is not as good. We have to accept that and that there are problems with the relationship and the collaboration between the NHS and local authorities. It has tended to be the local authorities that have taken the lead on carers' issues. You have the contacts, and you set up the networks and the fora to enable individual carers to give you their views; therefore, you understand the needs of carers more than the NHS. As a committee, we have been concerned about whether the fact that the NHS may be appointed as the lead body puts at risk any of the engagement that is already there with carers within local authority areas.

[112] **Mr Gatis:** I do not believe that it should. Again, as we said, I think that it would help to strengthen some of that. In my own authority, we have produced a carers strategy along with the NHS, the Department for Work and Pensions, and the third sector. We would see this proposed Measure building on that. We recognise that the NHS is a very complex organisation, and our ability to influence parts of it is better than the ability of others, which has been the history of our engagement with the NHS as local authorities. Placing the responsibility on the NHS to lead this work will prove beneficial for us in developing further and getting into some of the areas that Moyna has indicated that we have not been able to get into before.

[113] **Darren Millar:** I have a supplementary question to ask. It is one thing to have a duty to develop a strategy within the proposed Measure. However, we also know that it includes a duty to implement that strategy once it has been developed, but very few financial resources are available, according to the memorandum, in terms of regulatory impact. There is very little cash available to help you to do that. Do you think that there is a significant risk that there will be a poverty of ambition within strategies that come forward because you simply do not have the cash to pay for the implementation?

[114] **Ms Wilkinson:** There is quite a long answer about the cash available to help a range of people, which I will not give you right now because we are acutely aware, in local government, that we have to do more with less. Although it is important to resource things, and although there are services for carers that would be able to expand and develop were there more resources, one of the most important things is listening to people and respecting them, hearing what they say and adjusting your contacts with them and your consideration of services because you have properly listened to people. It is quite humbling sometimes to realise that that can be the most crucial thing, and to see how modest some people's wishes are in relation to even services. It is about being listened to; making it understood that you are a crucial part of that person's life; and not cutting that person off. It is about respect. I know that that sounds a bit fluffy, but that is unbelievably important. We talked to parents of autistic young people a couple of years ago, expecting a flood of demand, as there were quite a few gaps. They formed their own pressure group. They have gone around Wales talking about what they wanted, which was a decent transition plan that was understandable to them. They wanted more consistency. So, they were able to point out that a certain bit works well. Therefore, if it works well there, why does it not work well elsewhere? That was about attitude and behaviour. I will not start arguing myself out of a job, and arguing that we do not need resources.

10.10 a.m.

[115] Of course we need resources. I know that the proposed Measure has been costed against the Scottish requirements. However, there are also considerations in terms of how you do something and what you are able to do with the money that you have available. Of course I would want more for carers, if there is more available. No-one is going to say 'no'. However, we are dealing with a lot of demands and the crucial bit for me on this one is the inclusion of behaviours and the adaption of services as you develop them, so that they take that into consideration.

[116] **Andrew Davies:** You mentioned consistency of services, and what is apparent from the performance of local authorities across Wales is the lack of consistency. That is a very striking issue. In fact, there is a huge variation in performance, from the good to the catastrophic in the case of child and family social services in my own local authority. To explore this whole area of national standards, consistency and regulation, you make the point in your submission that you think that it should be set within a national standards framework. Can you explain more about your thinking in this area?

[117] **Mr Gatis:** We are trying to put forward the view that in terms of the proposed Measure and how you determine whether it is successful, we would be looking for outcomes for carers. We would be looking at whether we were able to provide the right information for carers in the right way, at the right time. We believe that there are probably frameworks that exist that you could latch on to. I go back to the Better Government for Older People programme in 2000—the early years—and the work that the University of Warwick has done on how you move from consultation to engagement, when researchers developed a framework that you could assess yourselves against to determine what progress you were making. It is at that sort of level that we believe that the Assembly might be helpful in ensuring that level of consistency. It would help us to be able to measure ourselves against something, to see whether we are achieving the objectives of the proposed Measure in getting information and advice to individuals.

[118] **Andrew Davies:** One of the consistent themes that the committee has been exploring in this area is improvement in performance and consistency at a high level—we do not want consistency at a low level, obviously—and whether the legislative route is the right one. On this whole issue of inspection and regulation, in which I declare an interest as a former Minister, even where you have regulation and inspection through CSSIW, that does not stop local authorities from failing catastrophically. As I said about my own local authority's child and family social services, two CSSIW inspections still failed to prevent that local authority from spectacularly failing the young people in my constituency and other parts of Swansea. An unprecedented intervention board was set up as a result. A lot of us wonder whether legislation is the right way forward in terms of making sure that you have consistently high standards.

[119] **Mr Gatis:** Legislation is one thing; what the proposed Measure is proposing is implementation in terms of guidance and statutory instruments to give further detail to it. As I suggested before, I think that we need to work with the Assembly on that further detail in trying to determine how we can ensure that we are measuring the right things in the right way, and that those things will, as you say, seek to prevent catastrophic failure as far as possible.

[120] **Ms Wilkinson:** It is a very big question. Do you want to us answer a very big question or answer specifically in relation to carers?

[121] **Andrew Davies:** I am asking for your view.

[122] **Ms Wilkinson:** I came to Wales at a time of local government reorganisation, and I think that there has been some spectacular success in terms of the improvements that have happened in this regard in social services across Wales. I think that you have to balance that. I

am not saying that it is consistent enough or that it is perfect everywhere, but there are some lessons to be learnt from where it works. The balance is about how you get something to improve without having everybody so frozen by inspection that there is hardly any headroom for improvement. It is a difficult one, and I appreciate that, particularly in relation to carers.

[123] I hate having to say this, because it sounds so pathetic, but I really do not like one of the measures that we use at present. I do not say that about many of them, as I think that most are fine, but if we are using some of the measures properly to look at performance—I mean the measures in terms of the performance indicators—then we have to get them right. Bob talked about outcomes. We would wish to work with NHS colleagues to look at the outcomes that are improving things for carers, and that means including a number of different measures to get the whole picture of what it is like for carers and whether they are seeing any improvements. You have to look at questionnaires at the outset, and bits of mystery shopping. You have to look at the carers' experience and add that to some of the existing measures, because on one of them, we score quite low.

[124] We might score low in a number of things, and there might be a reason for that, but because you want to improve on that, you do something about it. When it is just about whether people are counting something in a slightly different way, I struggle with that, because it is not a true measure yet. Having said that, indicators take a bit of time to get established. So, you need some hard measures and you need some targets, but you also need to work towards outcomes that will improve bits, in which case, you might see some of that changing over time as opposed to immediately.

[125] **Eleanor Burnham:** Yr ydych yn mynegi pryderon y gallai'r Mesur arfaethedig ei gwneud yn ofynnol i ymgynghori â gofalwyr ynghylch gwasanaethau a ddarperir i'r bobl y maent yn gofalu amdanynt. Yr ydych yn pryderu y gallai eu barn wrthdaro. Sut y dylai'r Mesur arfaethedig fynd i'r afael â'r mater pwysig hwn?

Eleanor Burnham: You express concerns that the proposed Measure could impose a requirement to consult with carers on the services that are provided to those that they care for. You are concerned that it could lead to a conflict of opinion. How should the proposed Measure deal with this important issue?

[126] **Ms Wilkinson:** I agree that carers need to be consulted. We wanted to explain that, in practice, a range of situations can exist. We see wonderful situations and we also see situations in which things do not work quite so well. With Measures, there is the intention and there is the effect. We in ADSS Cymru merely wanted to see some balance which allows for occasions when the interests and needs of the cared-for are in conflict with those of the carer—there can be challenges and differences, too. Similarly, you can get situations such as the one that I encountered, where two sisters were caring for their elderly mother. One would say, 'Please don't send her off to hospital' all the time, while the other would say, 'You do everything—don't you dare leave my mum'. So, you have a real conflict about what is best to do. These are highly emotional and difficult circumstances. I do not envy you the task; we wanted some recognition of the fact that it is not always completely agreed. That is not to detract in any way from the need to consult with carers. It is also true that, sometimes, people will make plans for those who are cared for without any reference to the carer. One carer described it to me like this: 'My house isn't my own anymore. There are all these people whirling around and I make them a cup of tea'.

[127] **Eleanor Burnham:** A lovely convenience.

[128] **Ms Wilkinson:** Yes. So, it is just that particular point that there are circumstances in which this can be a highly charged issue, and it may be that you, as professionals going into that, separate out the needs of the cared-for from the needs of the carers.

[129] **Eleanor Burnham:** Mae Cynghrair Niwrolegol Cymru wedi cynnig mewnosod safon ofynnol ar gyfer ymgynghori ar wyneb y Mesur arfaethedig. Beth yw eich barn am rinweddau dull o'r fath?

Eleanor Burnham: The Wales Neurological Alliance proposed inserting a minimum standard of consultation on the face of the proposed Measure. What are your views on the merits of such an approach?

10.20 a.m.

[130] **Mr Gatis:** In the guidance, we would expect to see further information on how, at a high level, we should consult, so we agree that we would expect to see some minimum standards. The discussion might be about what those minimum standards should be, whether they are realistic, and whether we could deliver on them as a locality. However, in principle, I do not think that we would have difficulty with the idea of minimum standards. It goes back to the issue of setting frameworks and looking at how we move from consultation to engagement in delivering those things.

[131] **Eleanor Burnham:** So, you do not think that it is too prescriptive, based on what your previous evidence suggests? This is to give an improved and consistent approach.

[132] **Ms Wilkinson:** Consultation means that someone asks you about something, and that is it, but it should be more than that. It is about whether people are listened to and have played their part.

[133] **Eleanor Burnham:** Ruth Marks, our earlier witness, mentioned the word 'involvement'. Do you agree that it is a more appropriate term?

[134] **Mr Gatis:** Yes.

[135] **Ms Wilkinson:** Yes. It is always difficult to find the right word that defines exactly what is meant, but, for us in the trade, it is about involvement and engagement, and the degree to which individuals and their carers determine their care packages according to their needs. That is the journey that we want to be on.

[136] **Eleanor Burnham:** Yn olaf, ymdengys nad oes darpariaeth yn y Mesur arfaethedig i'w gwneud yn ofynnol i awdurdodau perthnasol ystyried unrhyw sylwadau a dderbyniwyd gan ofalwyr yn dilyn ymarfer ymgynghori. A oes angen darpariaeth o'r fath yn y Mesur arfaethedig? Credaf eich bod wedi ateb y cwestiwn, a dweud y gwir.

Eleanor Burnham: Finally, it seems that there is no provision in the proposed Measure to require the relevant authorities to consider any comments received by carers following a consultation exercise. Is such a provision needed in the proposed Measure? I think that you have already answered that question, to tell the truth.

[137] **Ms Wilkinson:** To be honest, it is a basic requirement of any consultation that there be some indication that you have listened and heard. You may not agree with people's comments, however, and there is a difference between hearing what people say and acting on it. For goodness' sake, you would say it to their face if you could. You are not going to say, 'Yes, I have heard you and I will now change that', because you often have to take a range of views into account in any consultation. However, you have to hear it, and, if someone asks you for something specifically, you should be able to justify why it is not possible. It is like having a straight conversation, as you would with anyone else.

[138] **Mr Gatis:** I agree with Moyna. It is implicit in the proposed Measure that we listen to what is said but, as Moyna said, we are constantly trying to balance differing views and perspectives, being reasonable to all parties, and coming to decisions about how we move

forward when we have differing views. Moyna talked about the subtleties and the tact that we need when we talk to carers and the cared for. It is about trying to balance some of those things, but I think that that is implicit in the proposed Measure.

[139] **Eleanor Burnham:** Mae'n ddrwg gennyf, ond mae gennyf un cwestiwn arall yr oeddwn wedi anghofio amdano. Caiff llawer o fanylion y Mesur arfaethedig eu darparu mewn rheoliadau. A oes unrhyw bryderon gennych am hynny, a beth ddylai fod yn y rheoliadau?

Eleanor Burnham: I am sorry, but I have one more question that I had forgotten to ask. Much of the detail of the proposed Measure will be set out in regulations. Do you have any concerns about that, and what should be included in the regulations?

[140] **Mr Gatis:** As always, we would be concerned about the balance of detail within the regulations. In our response, we talked about micromanagement being a concern, because we do not feel that it would be helpful to us in taking forward any proposed Measure. As we have said, it is about trying to balance the view of the Assembly Government in setting a strategic direction and the ability of authorities to deliver that strategy on the ground. So, we would want to have a discussion, as all partners would, about the detail of any regulations.

[141] **Mr Wilkinson:** To add to that—and we probably should have mentioned this when we were talking about the NHS—Bob and I were discussing before we came in that, under the former LHB structure, there was a carers' representative on the board.

[142] When looking at organisations' internal functions, it can be useful to give people specific responsibilities. For any of these things to work, they have to happen at the strategic and highest level and go through the middle levels to the front line. They have to permeate all the layers. It is important in any strategy implementation to ensure that all those layers are permeated. It is not about one person at the top being able to do X, Y and Z; it is about how you get that to happen throughout, which can be a little tricky.

[143] It can be important to signal some of the issues. How will it be scrutinised? Will it be scrutinised within the existing scrutiny arrangements? We have a number of scrutiny arrangements, so my first recourse would always be to ask what the existing arrangements are and whether they are fit for the purpose of scrutinising and ensuring that this has happened. In essence, we are back to wanting it to make a difference to carers. We want the time and effort to be directed towards them and for them to be listened to. We want that as an outcome. So, as public servants, which we all are, we will try to do the right thing. It is about getting the balance so that it makes a difference on the ground.

[144] **Andrew Davies:** I take it from what you are saying that you would want, or even expect, to be consulted on, if not involved in, the drawing up of regulations.

[145] **Mr Gatis:** Yes.

[146] **Ms Wilkinson:** Is that an invitation? [*Laughter.*]

[147] **Andrew Davies:** My experience of Government is that the road to hell is paved with good intentions. We will probably get a raft of regulations drafted by an official who has not been heavily involved in service delivery and so is doing it in a vacuum. While the legislative framework may be broad and far-reaching, you will be fairly constrained in interpreting and implementing that, as officials in local government and in the health service. In the current social services and healthcare climate, following the case of baby P, people are taking a very risk-averse line, and I am concerned that the regulatory framework will be incredibly detailed, which means that there will be more red tape constraining you. The whole idea of having a professional approach is to allow professionals to exercise their professional judgment. If you

want a mechanic to read the list, he will do that. That is why I have a big problem with this approach. What do you think about that?

[148] **Mr Gatis:** To return to my previous answer to Eleanor, we need a dialogue about this proposed Measure and carers. Local authorities, and social services particularly, have a great deal of experience, expertise and knowledge to support the function. I would hope that we would be very much involved in that. You are right that, inevitably, because of such incidents as the case of baby P, and issues with critical, vulnerable adults, there is a risk that we become risk averse and go back to trying to prescribe everything. We will never be able to prescribe everything. With this proposed Measure, there is no need to prescribe in the detail that you are suggesting, because it is about information, advice and advocacy, and we all agree that those things should be out in the open.

[149] **Andrew Davies:** However, most of the evidence that we have heard is that the changes that are needed have more to do with culture. Your point was that it is about leadership and having a clear ethos and clear values.

[150] **Ms Wilkinson:** If you impose a range of heavy regulatory processes, you can sometimes kill the very thing that you are trying to create. I appreciate that the difference between intention and effect is huge. I have said that before, and we face it time and again and write it in every complaint letter. You have to think about how something will be interpreted and what effect it will have. It is the effect that we are interested in, as you can tell. It is not about processes; it is about outcomes and making a difference that is positive for carers.

10.30 a.m.

[151] One has to remember that, and simplify it so that people can get on with doing the job. A lot of the really positive work that has been done with carers was not done within a huge regulatory framework at all; it happened because people went away and did it, and listened and worked. I know that that is not enough; I am not a fool. However, we need that balance: you have to allow excellent work to grow and thrive, and you have to motivate and develop people as well as add controls.

[152] **Mr Gatis:** We would see—or certainly I would see, although I am not necessarily speaking for ADSS—the single most important aspect of this proposed Measure as being this duty on the NHS to take account of carers, and the provision of information to carers. Our council has a carers’ strategy that the NHS has signed up to, and 10 of the 22 actions that we are seeking to deliver over the next five years relate to information and advice. That is where this proposed Measure came from. It came from carers, with a groundswell saying that information and advice is critical to help and support them in doing that. We are not getting that at the moment. It is inconsistent, and the proposed Measure helps to drive and direct public services to take account of that.

[153] **Ms Wilkinson:** It makes it important. Bob and I both work closely with our health colleagues, and it is pretty good, but it is patchy. I am not just talking about Wales. The service that my mum got when my dad was dying was absolutely brilliant. That was at Newcastle General Hospital, which is in a horrible building, but it offered a fantastic service. However, you also hear stories that are completely different, and it should not be that different.

[154] **Andrew Davies:** It is how you get that effect.

[155] **Ms Wilkinson:** Absolutely. That was down to the staff, not the regulations. The regulations are the same everywhere. It was the staff and the management who made the

difference, by understanding and listening to people and treating them like human beings, understanding their emotions and what they were going through. That is money in the bank, and no set of regulations can necessarily create that, but you can promote it through all the levels, as I mentioned.

[156] **Mark Isherwood:** Before we come to the end of the session, do you wish to make any closing remarks, or address any issues that we have not questioned you on?

[157] **Ms Wilkinson:** I think that we have covered everything, but if there are other questions that you wish to ask, as a committee, we would be happy to come back. ADSS Cymru would also welcome being a part of the drafting. Thank you for giving us this opportunity.

[158] **Mark Isherwood:** The clerks will send you a transcript of today's proceedings for you to check and correct, if necessary, before the final version is published. It just remains for me to thank you both formally for attending today and giving evidence to the committee. I wish you a safe journey back to your respective counties.

[159] I welcome the witnesses from Barnardo's Young Carers to the final session this morning. Thank you very much for attending. We look forward to hearing your views on the proposed legislation. You are probably aware that much of the evidence that we have heard as a committee has related to young carers and young carers' issues, and therefore we look forward to hearing your opinions and views over the next 25 minutes. Please introduce yourselves, so that our clerks can have an accurate record.

[160] **Mr Ramzan:** Hello. My name is Muz and I am from Barnardo's Young Carers.

[161] **Ms Spokes:** My name is Hannah and I am also from Barnardo's Young Carers.

[162] **Mr Andrews:** I am Richard Andrews, and I represent Barnardo's Young Carers.

[163] **Mark Isherwood:** Just to let you know, some people may want to ask questions in Welsh. If you do not speak Welsh, there are headphones in front of you, with the simultaneous translation on channel 1. Channel 0 may also be used to amplify the sound if you are hard of hearing.

[164] I will start with the first question of this session, when I find it. I apologise, my papers are completely out of order.

[165] We have heard evidence suggesting that the aims of this proposed Measure could be met through existing legislation, and some evidence has suggested that carers are already being provided with adequate information from local authorities and the national health service. Do you agree or disagree with that and do you think there is a need for this proposed Measure?

[166] **Ms Spokes:** There is a need for this proposed Measure because, although other laws are in place, in my view not enough information is being filtered down to young carers.

[167] **Mr Ramzan:** My answer is basically the same. Not enough information is given to young people. That is our impression.

[168] **Mark Isherwood:** Thank you. We will move on to questions from Leanne.

[169] **Leanne Wood:** Some of the people who have given evidence to us in this committee have said that young carers should be mentioned specifically on the face of the proposed Measure, and that if young carers are not mentioned, some young carers could be missed out.

What do you think about that?

[170] **Mr Ramzan:** As you say, that would leave some people out.

[171] **Ms Spokes:** If we are referred to specifically as young carers, we think that other carers, such as older carers, might be missed out. So, we think that it would be a better idea to state ‘carers of all ages’ so that no-one is missed out or discriminated against—everyone, of all ages, would be included then.

[172] **Leanne Wood:** There is another piece of legislation going through this Assembly—which is not being considered by this committee, but by another committee—which is the LCO on vulnerable children. The Deputy Minister has told us that young carers will be covered by that legislation. However, the problem with that is that all young carers would be classed as vulnerable. What do you think about that? Do you think that all young carers are vulnerable or do you think that some young carers do not fit into that category?

[173] **Ms Spokes:** We would agree with that. I am a young carer, but I do not consider myself to be a vulnerable person. Other young carers might. It depends on the individual’s situation—who they are caring for and what the needs of the person whom they are caring for are.

[174] **Leanne Wood:** So, some young carers are vulnerable, but not all.

[175] **Ms Spokes:** Yes, some might consider themselves to be vulnerable. It depends on their situation and how they feel about their situation.

[176] **Mr Ramzan:** There are negatives and positives. If you ask carers whether they want to stop support, they will say ‘no’, because they want to support. Basically, it depends on the situation, because people are in different situations.

10.40 a.m.

[177] **Leanne Wood:** Do you think that there is a danger that if, as a young carer, you are labelled as vulnerable, that might mean that social services would take an added interest in your situation? Do you think that there is a danger of that?

[178] **Ms Spokes:** Possibly. I also think that if you are labelled as a vulnerable young person, you are competing against other vulnerable people, such as those who have been taken into foster care, or who are in trouble with the police or who have mental health issues.

[179] **Leanne Wood:** There are varying degrees of vulnerable, then.

[180] **Ms Spokes:** Yes.

[181] **Leanne Wood:** Do you have anything to add to that?

[182] **Mr Ramzan:** No, I cannot think of anything.

[183] **Mark Isherwood:** If, later, you think of anything that you would have liked to have said, you will get a chance to do that, or you can include it in your answer to other questions. So, do not worry if your mind goes blank; it is a difficult situation. If it comes back to you, we will be glad to hear from you later.

[184] **Andrew Davies:** Thank you for coming in; I imagine it must be pretty scary. All the evidence that we have heard is from people who either provide services or who represent

carers. I am interested in your own experience. What would you like this piece of law to do? In what way would things be different for you as young carers?

[185] **Ms Spokes:** We would like it to ensure that we are given support, that our needs are tended to, and that the right information is given to us when we feel it is necessary. It should be information that is appropriate and that we feel is specific to us. So, I would like it to be there for support.

[186] **Andrew Davies:** How involved would you like to be in making sure that services are tailored to what you need?

[187] **Ms Spokes:** Young carers should be quite involved in that, because you are catering for them. It is no good asking someone else what young carers would like; go ask them. It is up to them, and the important thing is what they feel is needed—when, where and how and so on.

[188] **Andrew Davies:** In my experience, in Flintshire in north-east Wales, in the foster services—although I know that that is a different service—young people were heavily involved with the local council and others to make sure that the services were designed for their needs. So, how would you want to be involved in that sort of thing?

[189] **Ms Spokes:** I have previously done some work with the young carers' network. A couple of young carers meet to discuss things that might be bothering us and how things could be put in place to help. In relation to travel, for example, there could be bus passes for young carers, because they might not be able to afford the bus as it costs £2 to get into town, and things such as that. We are helping to design an education pack for schools to make them more aware of young carers, how to identify them, how to help them, and what services to get in touch with to make sure that they are catered for.

[190] **Darren Millar:** I am interested to know a little more about your situation and the sort of support, if any, that you can get from the local authorities or the NHS in your area. What sort of information do you get at the moment? When you were first discovered as a young carer, what did the council or the NHS do for you?

[191] **Ms Spokes:** In my case, my brother and sister have autism. My sister is 15 and she cannot speak. My brother is 16 and he has Asperger's syndrome. He is in the special needs unit in Duffryn High School. My mum is now disabled because she had leukaemia, but because she is still able bodied and does not have any mental health issues, she is the primary carer. I am there to help her when she needs help, if she is having a bad day or whatever. So, I personally do not get a lot of information because it all goes through my mum because she is the parent.

[192] **Darren Millar:** So, there has been no discussion with you at all about the support that that may be able to give you or about help or allowances that your school might be able to make if you need time off and so on.

[193] **Ms Spokes:** No.

[194] **Darren Millar:** What about you, Mr Ramzan?

[195] **Mr Ramzan:** I look after my mum, but the main carer was my dad. If my dad needed help to look after her, that is what I used to do. So, everything is busy. Now, I am starting to look after her completely.

[196] **Darren Millar:** It sounds as if you have not had any involvement or that your opinion

has not been sought; you have not been asked what support might be helpful to you, and you mentioned a simple thing such as a bus pass to be able to get out and get a break now and again.

[197] **Ms Spokes:** If I need any questions answered or if I need to find anything out, I go straight to Young Carers, because that is the only way I know how to get information.

[198] **Darren Millar:** No-one has been designated as someone who could give you that support or advice.

[199] **Ms Spokes:** No.

[200] **Darren Millar:** It is important that we get that on the record, Chair, because, as Andrew said earlier, we have spoken to many different organisations, but when you have young carers coming in telling us how it is for them, it is striking.

[201] I want to ask about one issue that has cropped up while we have been chatting about these plans for new laws to support carers. The Deputy Minister, when she has spoken to us as Assembly Members, has said that she wants certain parts of council services to engage with the health service initially in order to develop these strategies—these bits of paper that will say how they will deliver this new information, advice and support. She has talked about housing and social services as the two council departments that will initially be geared up to work with the NHS to deliver this strategy, but she has not talked about education services. What do you think about that?

[202] **Ms Spokes:** I think that she has missed out on something that is really important, because every young person in the country is entitled to an education—that is where they spend most of their time. Five hours a day, five days a week is a lot of time; you spend more time in school than you do at home. I think that a lot of young carers could be missed in the identification process, because schools are not aware of them or they just label them as troublemakers.

[203] **Mr Ramzan:** For example, in school, I used to get bullied and be misunderstood and I used to get a lot of coursework and the teacher did not know about my situation and she did not really understand. So, I went to Richard and Becky at Young Carers and we set up a meeting and talked to the headteacher and that is how I got my support and it started to be much easier. I did not get the grades that I should have, because of the lack of support in school.

[204] **Darren Millar:** That is interesting. So, even though social services were supporting your dad—or your mum, in your case, Ms Spoke—they were not talking to the schools that you both attend to say, ‘Look, you need to understand that the situation at home is such that occasionally it will be difficult for them to get homework in on time and you need to be aware of these things.’

[205] **Ms Spokes:** I attend Duffryn High School and there is a collaboration with Hartridge High School. Up until a few weeks ago, my teacher at Hartridge was not aware that I was a young carer, so even though there is collaboration between those schools for sixth formers in Newport, the schools are not speaking to each other.

[206] **Darren Millar:** This, again, is very important evidence. We talk about local authorities being one of the relevant authorities in developing the strategy, but it does not refer to ‘local education authorities’, which we might need to add to the list, given the information that we have just had.

10.50 a.m.

[207] **Eleanor Burnham:** I am really pleased that you mentioned that, because when I was dealing with kids who were excluded across north-east Wales, that was one of the big issues. I am very pleased that Darren has highlighted that.

[208] I will ask my question in Welsh. The translation is on channel 1.

[209] Mae un adran o'r Mesur arfaethedig yn trafod ymgynghoriad. Gwn fod hyn wedi'i drafod yn barod, ond hoffwn ofyn cwestiwn ynglŷn â phwerau newydd i'r Gweinidogion i gyd, nid dim ond yr un sy'n delio â'r maes hwn, i wneud rheoliadau er mwyn sicrhau bod y strategaeth newydd yn caniatáu ymgynghori rhwng yr awdurdodau perthnasol a chi fel gofalwyr. A ydych yn credu y gall hyn alluogi gofalwyr ifanc fel chi i ddylanwadu ar gynllunio a datblygu gwasanaethau addas? One section of the proposed Measure mentions consultation. I know that this has already been raised, but I would like to ask a question about the new powers for all Ministers, not only the Minister who deals with this field, to make regulations to ensure that the strategy allows consultation between the relevant authorities and you as carers. Do you believe that this will allow young carers like you to influence the planning and development of appropriate services?

[210] **Mr Ramzan:** I do not think that it should be a requirement. Carers of all ages should be consulted and given the opportunity to offer their opinion.

[211] **Eleanor Burnham:** Okay, so do you think that Welsh Ministers should have powers to make regulations to ensure that this consultation between authorities and you happens, so that you can influence adequate planning and development? As we have just said, education is an area that is not being discussed at the moment, but we will be making a note of that.

[212] **Ms Spokes:** Carers of all ages should be considered in this process. Young carers have to be included. As I said before, it is all because of them; it is no good not including them.

[213] **Eleanor Burnham:** So, you need to be there at the beginning, at the planning and development stage, rather than at the end when they have done it and have not talked to you.

[214] **Ms Spokes:** Yes.

[215] **Andrew Davies:** A lot of what we have been talking about is making sure that you have the right information. I know from talking to young people from a wide range of different backgrounds that, for them, it is important that they are involved right from the beginning and are engaged so that they get the services that they want. However, a lot of it is about information. You have referred to that in giving evidence this morning.

[216] From what you know about this piece of law—the legislation that has been drawn up—has that area been covered? That is, making sure that the information is in the right form.

[217] **Ms Spokes:** I think that the language could be a bit clearer.

[218] **Andrew Davies:** You have to be a lawyer to understand it. [*Laughter.*]

[219] **Ms Spokes:** Yes. It is quite vague. It says that the Minister 'may'; it should be a requirement rather than a 'may'. It seems that something can be done, but it is not a necessity. It should be in clear and definite language. It should say that this is a requirement and should read 'must'.

[220] **Andrew Davies:** It should be tougher and much clearer.

[221] **Ms Spokes:** Yes.

[222] **Leanne Wood:** [*Inaudible.*]

[223] **Mark Isherwood:** From what I have heard today, you should both be getting very high grades in school. We have come to the last question, but it is quite a big one. What are the points that we have not raised in the questions so far that you would like to raise before we bring the session to an end?

[224] **Mr Ramzan:** The only support that I receive is from the Young Carers Network.

[225] **Mr Andrews:** What kind of support have you had? What has helped you?

[226] **Mr Ramzan:** The network has provided me with support during the times that I have needed to go out. I could have explored and gone out, and when I needed a chat, the network was there. The network also helped when I needed any information. For example, with doctors, if there is a situation going on with my mum, such as if she is ill, they do not explain it to me properly. So, I always go to the network to get things explained. I tell the doctors that I am a young carer, but I sit there and they ignore me. That is what I do not like. If we have a hospital appointment and the doctors know that my mum is ill, I should go into the hospital with her, chat with the doctor and ask what the problem is. However, that does not happen and I always get left out. I do not like that. So, I always go to Richard or Becky for help to understand the situation.

[227] **Leanne Wood:** From what you have both said this morning, you seem to receive an awful lot of support from the network. What about all those young carers out there who do not know about support groups? How do you think they are faring?

[228] **Ms Spokes:** That is where education services, social services and health services should be working together to raise awareness of the young carers organisation. I feel that there is a lack of understanding with the education services, which are the services that I deal with the most. I am not sure about social services and health services. There are not many people in those authorities who have been young carers or cared for anyone in the past. This is about knowing that there is support and understanding.

[229] **Leanne Wood:** Where is the best place for young carers to be identified? You mentioned previously that you go to the hospital with your mother, and that seems to me like a great opportunity for a health professional to say to you, 'You are a carer; this is information on what Barnardo's does'. Schools could be doing that as well. Do you think that this should be an issue for schools or health services, or should everybody have a responsibility?

[230] **Ms Spokes:** I think that it should be everybody. None of them are more important than the other, and without one of them you cannot function. They all need to communicate with each other.

[231] **Leanne Wood:** And you feel that they are not doing that at the moment.

[232] **Ms Spokes:** Yes.

[233] **Darren Millar:** How did you first find out about the network? Who gave you the contact details?

[234] **Ms Spokes:** My mum saw a poster and got in touch with the organisation.

[235] **Darren Millar:** So, there was no referral from social services or the local hospital.

[236] **Ms Spokes:** No. My mum saw a poster, rang the network up and said, ‘My son and daughter are disabled and I am disabled. Is Hannah considered a young carer?’

[237] **Darren Millar:** Was the situation the same with you, Mr Ramzan?

[238] **Mr Ramzan:** Yes, basically. I was referred by my mum’s solicitor, I think. There was another organisation called BAWSO and I was referred by that organisation to the network.

[239] **Darren Millar:** So, you both found different routes to the support that you were able to access through the network. There has been no statutory body—no council or health service—involved in giving you the information that the network is there to provide support, advice and guidance. I find that shocking.

[240] **Eleanor Burnham:** We are living in very complex times. A lot of people, in my opinion, hide behind something called data protection. You talked about the fact that nobody talks to you when you go to the hospital and so on. Has anybody ever explained why they do not talk to you? Have they ever said that what is going on with your mum is confidential? That happens a lot, and I am wondering whether we should make a note of it. As you said, information should be shared.

[241] **Ms Spokes:** We understand that there are confidentiality agreements between doctors and patients. As I said before, however, my sister is 15 years old and she cannot speak, so it is no good a doctor telling her a diagnosis on her own, because she could not tell anyone.

11.00 a.m.

[242] **Eleanor Burnham:** Should we make it explicit? You probably know about it from reading all of this, because you are very intelligent and have been very good at understanding everything that we have been talking about, which is brilliant. Do you think that we should make a note of this, because the Deputy Minister says—quite rightly, for some of us—that the health authorities should lead on this? Therefore, the health authorities should understand that they need to do this very basic thing, namely, to tell you and include you.

[243] **Ms Spokes:** Yes.

[244] **Eleanor Burnham:** I would like to make a note of that, because confidentiality and data protection are often used as a smokescreen for something that is very basic and important.

[245] **Mark Isherwood:** The clerk has made a note of it.

[246] **Andrew Davies:** I do not think that that has anything to do with referral, which is essentially what—

[247] **Eleanor Burnham:** No, it was confidentiality—

[248] **Andrew Davies:** May I finish? The point is that, for what you needed, Hannah, you were lucky that somebody, somewhere, in some organisation, was able to refer you to Barnardo’s Young Carers. I think that Leanne’s question on how many other young carers are out there who are not aware of what is available is crucial. This proposed Measure is trying to address one of those big gaps.

[249] **Mark Isherwood:** We talk about signposting, Hannah. It basically means that the person who is working with you, in whatever context, tells you about the support that you can get without having to be asked. That is what we are talking about.

[250] I will ask one final question, because we have to finish in three minutes' time. You referred very positively to the support that you got from Barnardo's Cymru. If this proposed Measure is passed and improves things, and there is proper consultation and proper information coming to you, would you prefer your first point of contact to be with an organisation like Barnardo's or with somebody working for the council or the local health board?

[251] **Ms Spokes:** Personally, I would prefer it to be with Barnardo's Young Carers, because I have been with them for eight or nine years now. There is a trust there. You have the trust, the support and the confidentiality. It is all there.

[252] **Mark Isherwood:** Thank you. We have come to the end of the session and everything that you have said today will be written down and sent to you so that you can check it before it is finalised to make sure that we have an accurate record. We cannot take out things that you said that you did not want to say, but if you think that we have got it wrong, you may say so before the final version is published.

[253] It just falls to me to thank all three of you for attending today. I hope that it was not too nerve-racking. Now that you have done it once, you will be experts. Thank you. Have a safe journey home.

[254] **Ms Spokes:** Thank you.

[255] **Mark Isherwood:** Members, I have just a few closing remarks. The next meeting of this committee will be on Wednesday, 24 March, notwithstanding other matters. That will be our final evidence session, when we will be taking evidence from the Deputy Minister for Social Services, Gwenda Thomas, and we will be considering the key issues and the summary of consultation responses.

[256] **Eleanor Burnham:** 'Notwithstanding other matters'—when will a decision be made?

[257] **Mark Isherwood:** It is a matter for Members to notify the clerk if they are not intending to attend the committee. If we know that, discussions will ensue between the clerk and me to decide on the best course of action to take.

[258] **Leanne Wood:** What if we do not have a Deputy Minister at the meeting?

[259] **Mark Isherwood:** If we do not have a Deputy Minister, we cannot take evidence from the Deputy Minister.

[260] **Leanne Wood:** Thank you.

[261] **Mark Isherwood:** We will cross that bridge when we come to it. At the moment, the meeting is scheduled for next Wednesday morning, as normal. As far as I am aware, the Deputy Minister has not yet indicated that she will not attend. If she indicates that she will not attend, we will report back to Members.

[262] **Eleanor Burnham:** Thank you, Chair.

[263] **Mark Isherwood:** Do any Members have further points to make before we conclude? I

see that no-one does. Therefore, I declare the meeting closed.

Daeth y cyfarfod i ben am 11.04 a.m.
The meeting ended at 11.04 a.m.