



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

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

**Dydd Mercher, 24 Chwefror 2010
Wednesday, 24 February 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

Alun Davies	Llafur Labour
Mark Isherwood	Ceidwadwyr Cymreig (Cadeirydd y Pwyllgor) Welsh Conservatives (Committee Chair)
Val Lloyd	Llafur (yn dirprwyo ar ran Andrew Davies) Labour (substituting for Andrew Davies)
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Leanne Wood	Plaid Cymru The Party of Wales

Eraill yn bresennol
Others in attendance

Joseph Carter	Is-gadeirydd Cynghrair Niwrolegol Cymru a Chymdeithas MS Cymru Vice Chair of the Wales Neurological Alliance and MS Society Cymru
Carol Thomas-Wyllie	Cymdeithas Clefyd Niwronau Motor Motor Neurone Disease Association
Keith Towler	Comisiynydd Plant Cymru Children's Commissioner for Wales

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	Dirprwy Glerc Deputy Clerk
Bethan Roberts	Cynghorydd Cyfreithiol Legal Adviser

Dechreuodd y cyfarfod am 9.00 a.m.
The meeting began at 9.00 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

[1] **Mark Isherwood:** Bore da a chroeso. **Mark Isherwood:** Good morning and welcome.

[2] Val Lloyd has joined us this morning and is substituting for Andrew Davies, who has been double-booked. He has replaced Lesley Griffiths as a member of this committee. We have not received any other formal apologies.

[3] I remind everyone that, in the event of a fire alarm, you should leave the room by the marked fire exits and follow instructions from the ushers and staff. No test of the fire alarm is forecast for today. Please switch off all mobile phones, pagers and BlackBerrys as they

interfere with the broadcasting equipment. The National Assembly for Wales operates through the media of English and Welsh. Headphones are provided, through which simultaneous translation may be received. For those who are hard of hearing, the headphones may be used to amplify the sound. Interpretation is available on channel 1, and a verbatim broadcast can be heard on channel 0. Please do not touch the buttons on the microphones, as doing so can disable the broadcasting system. Please ensure that the red light is showing before speaking.

9.01 a.m.

**Mesur Arfaethedig ynghylch Strategaethau ar gyfer Gofalwyr (Cymru)—
Cyfnod 1: Sesiwn Dystiolaeth 2
Proposed Carers Strategies (Wales) Measure—Stage 1: Evidence Session 2**

[4] **Mark Isherwood:** Legislation Committee No. 5 is considering the general principles of the Proposed Carers Strategies (Wales) Measure, and must report by 7 May this year. The public consultation was launched on 4 February and will close on 18 March. The Deputy Minister for Social Services, Gwenda Thomas, gave evidence at our meeting on 10 February. Today's meeting is therefore our second evidence session.

[5] The first to provide evidence is the Children's Commissioner for Wales, who will be followed by the Wales Neurological Alliance. I welcome Keith Towler, the Children's Commissioner for Wales. Could you please introduce yourself for the record?

[6] **Mr Towler:** My name is Keith Towler, and I am the Children's Commissioner for Wales.

[7] **Mark Isherwood:** The paper submitted by Keith has been circulated to Members. We have a number of questions for you, Keith, based on your paper. I will ask the first question. In your opinion, is there a need for the proposed Measure and do you support its overall aims?

[8] **Mr Towler:** Yes, there is a need for the proposed Measure. It provides an opportunity for a holistic and comprehensive approach. It is an opportunity to incorporate the United Nations Convention on the Rights of the Child as far as young carers are concerned. Issues to do with engagement and consultation are also key, and I am pleased to see that they are included in the proposed Measure. However, I am disappointed that the proposed Measure does not fully incorporate young carers into all aspects of the strategies to which it refers. Section 2(1)(a) of the proposed Measure refers to advice and information, but, from my reading of the proposed Measure, the key point is that everything else for young carers seems to be excluded from it. This is an ideal opportunity to make sure that young carers are incorporated into a Measure that takes a holistic approach. We are in danger of segregating the needs of young carers by dealing with some in the proposed Measure and others in the LCO on vulnerable children. I do not understand why that has happened.

[9] **Leanne Wood:** Do you think that the aims of the proposed Measure could be achieved using the existing legislative framework?

[10] **Mr Towler:** History suggests not. My office produced a report last year called 'Full of Care', which was a piece of work that we took forward with young carers across Wales—we were assisted by the Powys young carers service in particular. We got the views of children and young people from across Wales who are carers. When producing 'Full of Care', we constantly heard from young carers about a lack of co-ordination and clarity as to who would provide services, how they could be provided, and indeed whether young carers were entitled to services. There was a real issue about whether they knew that they could have services.

When talking to professionals, we found that there was a real issue about the identification of young carers, and at what point agencies identify a young person with a caring responsibility and say, 'Yes, you are a young carer and are in need of support.' My feeling is that existing legislation has so far failed to really consider the identification of young people as carers and how we could then support and provide services for those young people.

[11] **Leanne Wood:** You state in your evidence that you disagree that the needs of young carers can be addressed by Measures introduced using the powers under the LCO on vulnerable children and that you believe that their needs could be fully addressed using the powers in the carers LCO. Can you explain your reasoning behind that?

[12] **Mr Towler:** When the carers LCO was going through there was clear discussion and awareness within the Welsh Government about the specific needs of young carers. Much of the discussion around the LCO encapsulated young carers as being a key part of anything that we would take forward around carers. That seemed important and I really welcomed that approach. We are now in a situation where we have a proposed carers Measure that, in my reading of it, identifies the provision of advice and information, which applies to young carers, although other provisions within the proposed Measure do not appear to apply to them and relies on the vulnerable children LCO.

[13] A few things struck me about that situation. Some young people with caring responsibilities do not identify themselves as vulnerable, so there is a real issue about where they sit within this. To be frank, I feel that those children and young people who we currently describe as children in need, over and above those children of huge concern to local authorities and health authorities, should be right up there on the priority pecking order if there is a safeguarding or a child protection issue. There is a whole range of children who we would describe as children in need. The proposed carers Measure is an opportunity to look at the young people who are children in need and to say to them, 'Within this one piece of legislation, we're going to encapsulate your rights and entitlements as young carers', because it seems to me that it currently separates these things. I know that that is contrary to the advisory group's recommendations to the Deputy Minister, but I do not agree with its conclusions that to separate those two things and to rely on the provision of support and services within one piece of legislation and advice and information in another piece of legislation is robust enough.

[14] **Leanne Wood:** You are saying, in effect, that you think that some young people will slip through the net if they are young carers but are not considered vulnerable children, for the purposes of the vulnerable children's LCO, and therefore they will not have access to services other than the advice and information services. Is that right?

[15] **Mr Towler:** That is right. What we currently know about the number of young carers is pretty shameful; we think that there are about 1,000 known young carers in Wales. What the 'Full of Care' report and others demonstrate is that we could be talking about as many as 10,000 children and young people in Wales who might be young carers and who might require some level of support and assistance. Most of those young carers would describe their lives as 'normal'. On the vulnerable children LCO and assessments around vulnerable children, do we really think that we would need to go through the full vulnerable children assessment to provide some kind of support for a child who may need help in getting to school in the morning and in ensuring that someone else feeds their mum? We probably do not. To describe those children as vulnerable, with the full set of assessment procedures that are in place, seems bureaucratic and over the top in a system that could identify some required support to a young person. The vulnerable children LCO seems a bit heavy in relation to the needs of some of these young people. There are many young people who we could be talking about here, but, to be honest, using the vulnerable children LCO as a way of doing that seems bureaucratic and over the top.

[16] **Leanne Wood:** The Deputy Minister stated in Plenary that the carers' stakeholder group, which you referred to earlier,

[17] 'outlined a range of alternative opportunities that exist through our Proposed Children and Families (Wales) Measure, through approaches associated with our policies to address child poverty and through the children and young persons strategies that would address more fully the needs of young carers, including those carrying an inappropriate burden of care.'

9.10 a.m.

[18] Do you think that those opportunities offer more scope for addressing the needs of young carers in a holistic way?

[19] **Mr Towler:** There is certainly some scope. The issue there, to use your words, is the holistic model. In discussing the needs of young carers, we are talking about the needs of families and making sure that we identify that, if someone requires care at home, which is being provided by another adult or a child, the family gets the support it needs to provide that care. So, the answer to your question is that there is some scope in this.

[20] In relation to issues like child poverty, I echo the point that I made about vulnerable children: not all children and young people who are carers will be living in poverty. So, that is not broad enough. Thinking about what young people tell me about the stigma of being a young carer, and about trying to explain to their school, or whoever, about their responsibilities at home, they do not want to be labelled as a young carer or someone with a particular problem or issue. They just want a bit of understanding. So, there is scope there. The proposed Measure offers the opportunity to ensure that we have a comprehensive, holistic Measure that begins to think through the rights and entitlements of everyone caught up in that process. Therefore, I wonder why we would exclude young carers from this proposed Measure as it is currently drafted, other than in relation to advice and information, and think about provision of services elsewhere. That seems to me to be an opportunity lost.

[21] **Mark Isherwood:** I will ask a supplementary question before calling you, Alun. You referred to the possibility that there may be up to 10,000 young carers. Barnardo's in Flintshire pioneered the integrated family support team model outlined in the children and families Measure. It told me that, although it has supported 150 young carers, it estimated that there were possibly 2,000 in that county alone. Do you feel that 10,000 is a fairly conservative figure?

[22] **Mr Towler:** Part of the shame of this is that we are scratching at the surface in trying to establish the number. It is important, particularly with regard to your role, that we understand why we do not know that figure. A number of families will report—and this certainly came through in 'Full of Care'—that most young carers would see their life as being normal. Many adults who recognise that their children have a caring responsibility might not want to identify those children as young carers. Some might feel that their children would be taken away from them and put into care. So, the fact that people are reticent about coming forward and acknowledging that their son, daughter, niece or nephew has a caring role is part of the problem.

[23] The fact that we are still getting to grips with the number of young people who are carers is quite shameful for us. We need to understand the reason for that reticence. This may be a matter of the state interfering in something and not recognising that these young people have a right to a childhood too and that our responsibility as adults—whether we are parents or whether we are working, as we all are, to try to make things better for children and young people—is to ensure that they have the support needed to fulfil this role. So, we need to

understand why we do not know the figure. You might be right to say that it could be higher than 10,000. A considerable number of children and young people are in that position.

[24] **Alun Davies:** Thank you for your evidence. The Deputy Minister has told us that it is not necessary to refer specifically to young carers because the proposed Measure embraces all carers. Are you satisfied with that?

[25] **Mr Towler:** I do not doubt at all Gwenda Thomas's commitment to young carers. Allow me to say that, and I mean it 100 per cent. I have met Gwenda to discuss this and other issues, and I am completely clear that our Deputy Minister has a real understanding. However, the distinctions between the provisions in the proposed Measure isolate what it will do for young carers, namely provide advice and information. I find it difficult to come to terms with the other elements, particularly sections 2(1)(b) and 2(1)(c), namely that authorities will decide which services are to be provided for any carer outside the scope of the proposed Measure and will consult young carers who come outside its scope, given that this legislation is supposedly looking at the responsibilities of all carers, including young carers.

[26] On where we are at the moment, the Deputy Minister is completely committed to young carers, and says that this will be picked up under the National Assembly for Wales (Legislative Competence) (Social Welfare and Other Fields) Order 2008 on vulnerable children. I take some comfort from that, because I know that Gwenda Thomas is committed to it. Nevertheless, we all know that Governments and personalities change. I would far prefer to see young carers included on the face of this proposed Measure.

[27] **Alun Davies:** I understand the points that you make, including in your written evidence. However, I do not understand why an explicit reference is required because the strategies that authorities will be required to make will be subject to consultation and, I assume, to agreement. Therefore, the needs of particular groups within the caring community will be addressed at that point. Is it really necessary to put all this on the face of the legislation? Why do you not think that the process of creating these strategies is sufficiently robust?

[28] **Mr Towler:** On the point about the development of strategies, where young carers sit in such strategies is the key to this, as is the drafting of regulations and how the inspectorate functions to ensure that young carers receive the service and support that they require. This picks up on Leanne's point at the beginning on whether legislation works currently for young carers. The answer is, 'No, it does not'. However, I still come back to the point that it seems illogical that we have an opportunity to tidy up the legislation in relation to carers, and to package this in such a way as to place the needs of young carers firmly in legislation for them, but we are separating those elements so that we have advice and information working in one way, and direct support and assistance working through another stream. It seems to be messy. It does not seem to provide an opportunity for legislation to ensure that these children get the service that they require. If you were to have discussions, as I did, with some of the young people who were involved in this report, you would know that, to be frank, they do not care where they get the services and support from. The fact of this legislation proceeding will pass them by. The issue is how managers ensure that children who are young carers get the services that they need. I want this legislation to ensure that those people who are responsible for developing strategies ensure that young carers get the advice, information, support and services that they require, and are consulted. I would prefer to see that encapsulated in the proposed Measure, rather than being separated into two pieces of legislation.

9.20 a.m.

[29] **Alun Davies:** I understand that, and I agree that, sometimes, Governments prefer to legislate in two parts, and there is then, of course, a difference between the two. I am still not

entirely comfortable with listing groups of people on the face of legislation, however, as it implies that you do not believe that the process of creating the strategy is very robust, and that you do not have much faith in it. That is an interesting conversation to have at another committee meeting. It certainly implies to me that you do not have much faith in the system. Secondly, all these lists tend to be created through regulation rather than primary legislation, and so I find it a curious argument, because any organisation could come here to say, 'The people whom I represent should be included in this'. While I agree with you that Ministers come and go and Governments change, and so we need to have legislation that continues and is robust in that sense, I am not entirely comfortable that you have responded to the question of why these issues cannot be dealt with by regulation or by secondary legislation.

[30] **Mr Towler:** You are right. I guess that there is another discussion to be had about turning strategies and policies into practice. I am exercised by that point virtually every day, and, usually, I am unclear as to why certain children and young people do not get the services that they should get if clear policy practice and guidance is in place.

[31] **Alun Davies:** Sorry to interrupt, but would it be possible for us to have a note on that? If your experience of working within these strategies is as you say, perhaps we need to look again at this legislation, not simply in reference to children and young people, but also to the statutory framework in which these strategies are created. If you have any experience that might help us with that, it would be useful for us to look at in a more general way.

[32] **Mr Towler:** My last annual report provides a great deal of information about that exact point. In my last annual report, I made the very clear point that there is a big gulf between policy intent and practice on the ground, and the report is full of illustrations of how that comes to happen.

[33] **Alun Davies:** Perhaps you could circulate it again.

[34] **Mr Towler:** Yes.

[35] **Mark Isherwood:** Would you be happy for us to quote from that in our report, if we felt it appropriate?

[36] **Mr Towler:** Yes, absolutely. If you would like to have further hard copies of it, please let me know because we have trees-worth of them.

[37] The key to this is regulation. The bottom line for me is that I want this to be as watertight as possible. I want those people who are duty bearers towards young carers to be absolutely clear of their responsibilities. For that to be seen to be driven from one piece of legislation will focus their minds. I take the point that anyone could come here lobbying for any particular group. As we have seen, as Gwenda Thomas recognises, and as I think is recognised here, young carers are in a distinct and different place when compared with adult carers. They are a unique set of human beings going through a developmental phase all of their own: trying to go through their education at the same time as being a carer, and having rights and entitlements to a social life. They have a very distinct set of needs. As we have heard from the Chair, we could be talking about as many as 10,000, 15,000 or 20,000 children and young people. That is a significant number of young people requiring some level of support to get the education that they need and to access the kinds of services and support that they need. I take your point that you are still uncomfortable, but I think that I really need to bang this drum. I want this to be as watertight as possible, and including young carers on the face of the proposed Measure would make it watertight.

[38] **Leanne Wood:** I am unable to understand what the difference will be. What can an adult carer expect from this proposed Measure as distinct from a young carer? Can you

explain what a 19-year-old or a 25-year-old carer can expect from it that a young carer cannot? You say that it is messy, so is it just about things being tidy, or will it impact in a real way on the services that young carers can expect to receive as compared with their adult counterparts?

[39] **Mr Towler:** I will try to be clear. A health visitor going into a family situation might see that mum is the person receiving the care and dad is the principal carer, but the children in the family could also be undertaking a caring role. The impact of that situation on those children and young people should be easily understood but, too often, nothing happens for those young people. So, if we are in a situation in which a young person in that family is performing some caring duty every morning or running home from school at lunchtime to provide a meal for mum while dad is at work, what that young person is doing is not identified because no-one really understands that it is happening.

[40] **Leanne Wood:** Could they not be identified?

[41] **Mr Towler:** Yes, absolutely. That is the point that comes through in the 'Full of Care' report, which goes back to the point about the identification of the numbers of children and young people who are undertaking a caring role. We are not identifying sufficiently well the numbers of young people who have a caring role and responsibility. It is just not happening as it should be happening. Identification is a key issue, but people need to be able to say, 'My son is helping me at lunchtimes' without fear of retribution or of the child being taken away for being drawn into a caring situation. We need to be able to alleviate the situation. The caring responsibilities and the impact on children is quite distinct from and different to that of an adult carer, and much of that is to do with identification and assessment.

[42] **Leanne Wood:** So, do you think that more young carers would be identified if they were included on the face of the proposed Measure?

[43] **Mr Towler:** There stands to be more scope for identification if they are included, because it will focus people's minds, whether they work in health, in local authorities, or wherever. They need to start to think through their responsibilities and pick up on the fact that they have a responsibility to children in the family as well as to the person being cared for. I do not think—in fact, I know that that is not happening sufficiently well. Barnardo's also states that in the evidence that it has given to the Chair.

[44] **Leanne Wood:** Does that mean that existing strategies are failing?

[45] **Mr Towler:** The existing strategies are failing to identify and assess children who require support, advice and assistance.

[46] **Darren Millar:** Thank you for the written evidence that you have supplied. This proposed Measure places responsibilities on local health boards or NHS bodies, as well as local authorities to produce strategies. Should there be a responsibility on the NHS and local government, or should it be more appropriate to give all the responsibility to local authorities to produce those strategies?

[47] **Mr Towler:** It is right to identify the responsibility of the health service and local authorities, particularly if this is all about providing a comprehensive and holistic service. So, I am comfortable with that. In fact, it would be impossible to develop the kind of holistic package that we are talking about if that were not the case.

[48] **Darren Millar:** Is it appropriate for the legislation to suggest that the NHS should be the lead body rather than local authorities, given that local authorities have traditionally been the champion of carers and have predominantly provided the services to carers? Is that the

right approach?

[49] **Mr Towler:** There has to be a lead body to house any resource that becomes available or to take responsibility. However, there is always a danger when you identify a lead body of placing all the responsibility on it to ensure that things happen. That is a task for the regulations. I am reasonably comfortable for the functions of a lead body, the holistic and comprehensive package of support, and the local authorities' role in that to be identified in regulations. There is an opportunity with the new local health boards to think about what that lead role could be. I do not have a problem with taking the responsibility away from local authorities and placing it with the health bodies. However, there is an issue about how you identify the task of the lead authority in regulations.

[50] **Darren Millar:** The Deputy Minister has spoken a lot in evidence to committee and in Plenary about the need for consistency across Wales in the support available to carers. Will the production of a significant number of strategies for carers—potentially up to 22—deliver that consistent approach?

9.30 a.m.

[51] **Mr Towler:** It has the potential to do so. There is a key task, is there not, for those in receipt of those strategies? We ought to be better at looking at the plans and strategies that are coming in, and asking hard questions of them: to what extent will this deliver services for young carers? To what extent will advice and information be available? Please evidence how you will achieve that? That is critical to ensure consistency, so there is a task for the collator at a Welsh Government level to ensure that those strategies are robust. However, I agree with the Deputy Minister that there is an opportunity to create a more consistent response to young people who are carers and carers more generally. So, I think that I would welcome that.

[52] **Darren Millar:** The needs of young carers in north Wales are the same as for those in west Wales, for example. Why should we have 22 different strategies?

[53] **Mr Towler:** That is a big question. There is an issue about how services are provided to locally. I was in Mountain Ash recently with a group of young carers, and Rhondda Cynon Taf council is looking at how it commissions services for them. Those young carers have strong views about the current services that they wanted to make known to the people commissioning the services—they were broadly positive about them. It is about local delivery and gaining the confidence of the people who are in receipt of services. I do not know whether there should be 22 strategies or eight, but the big issue for me is whether young people have confidence in the services that they receive and are happy to vocalise their views if they see that something might change. That is the key: what local delivery looks like, and the extent to which young people are confident in the services that they receive.

[54] **Darren Millar:** The other point that you mention in your evidence is the need for a multi-agency approach. The proposed Measure focuses on the strategies to be delivered by local authorities and the NHS. Do you think that there is sufficient regard in the proposed Measure for third sector organisations, or the independent sector, if you like, or does there need to be more meat on the bones?

[55] **Mr Towler:** I am quite comfortable with the proposed Measure as it is. There will be an opportunity in regulations to be clear about the involvement of voluntary and third sector organisations in the delivery of services. Many of the young people who we came into contact with really valued 'Full of Care'; in fact, if you have an opportunity to look at the key parts of that report, I would urge you to do so. There is a simple set of questions asking young carers about their experience, and they rate their experience of social services, health and so on. The percentage scores for statutory services are not good, but the percentage scores for young

carers' organisations, which are largely voluntary sector organisations, are incredibly high. I would urge you to look at that. Young people value what local young carers' services, which are largely third sector organisations, are providing for them.

[56] **Darren Millar:** Going back to paying attention to young carers' needs specifically, in some families there are a number of people caring for an individual. It could be their partner and their children. Should there be some kind of specification on the face of the proposed Measure about secondary carers? The way that I read it, it is primary carers who will be consulted more than secondary carers. Is that something that you would like to see on the face of the proposed Measure?

[57] **Mr Towler:** That encapsulates what I was trying to talk about earlier, that is, the status of young carers within families. I would be happy to leave it to the lawyers to tell me whether that would deliver the kind of result that we want, but there is no doubt in my mind that many secondary carers are young people, and they are not being consulted, and not having their voices heard; in fact, they might be unaware of the impact upon them. If that kind of specification in the proposed Measure would assist us in moving some of this forward, then I would be pleased to see it.

[58] **Darren Millar:** What proportion of the estimated 10,000 to 20,000 young carers across Wales would be secondary as opposed to primary carers?

[59] **Mr Towler:** I find that question very difficult to answer; I really do not know.

[60] **Val Lloyd:** My first two questions are related to Darren's. In Plenary in January, the Deputy Minister said that, of the range of local authority services, she has decided to cover, in the first instance, social services and possibly housing. Given the important role of other local authority services, such as education, in identifying young carers, is that the right approach?

[61] **Mr Towler:** I am not sure, to be honest. I was a bit confused when I first heard that, because I was not entirely clear how you would be able to develop a comprehensive holistic service by first picking out one or two areas. You could have picked out any two of a number of areas, and said, 'Let us do something else and something else'. It strikes me that things are either comprehensive and holistic or they are not. You cannot have it both ways. So, we need some clarification from the Deputy Minister of what she meant. When I first read that it would be housing and social services, I wondered whether the Deputy Minister was referring to accommodation services within children's services or social services or whether she was referring to the housing department and social services. I would like some clarification, but the basic principle is that we are either in the game of providing a holistic comprehensive service for carers or we are not.

[62] **Val Lloyd:** That is clear; thank you for that answer. Staying with that issue, the proposed Measure refers to 'relevant authorities' and defines those. Could anything be added to that list?

[63] **Mr Towler:** No, I think that the list of four is pretty comprehensive. The one that strikes me is the listing of local authorities, because they cover so many areas. For example, education, which featured massively in our 'Full of Care' report, and which is a huge issue for young carers, would be encapsulated within the four authorities that are listed. However, that is one of the key issues: the list of four is fine, but the issue for the regulations is that, if we are thinking about this comprehensive service for carers, as far as young carers are concerned, almost every component of a local authority's function—education being right up there—has a responsibility to provide services and support for young carers. So, that is a key task for regulation. However, with regard to the proposed Measure, I am comfortable with the four relevant authorities that are listed.

[64] **Val Lloyd:** You mention regulation, and the proposed Measure contains enabling powers for the Ministers to implement and set out the detail of the preparation and publication of strategies for carers in regulations, orders and statutory guidance. Do you think that it strikes the right balance between the provisions in the proposed Measure and the regulation-making powers conferred on Welsh Ministers?

[65] **Mr Towler:** I think that balance is needed. I am trying to get my head around the negative and affirmative procedures of this place, and it strikes me that there might be an opportunity, when looking at the first set of regulations, for the affirmative procedure to be used before it is handed over completely for ministerial approval. It seems to me that the drafting of the regulations is one of the key tasks here and that the Deputy Minister might find it useful to think through the full implications of what is being discussed.

[66] **Val Lloyd:** I think that you have probably answered my next question, but I will just clarify the point for the record. Do you think that the powers are sufficiently significant to require the use of the affirmative procedure?

[67] **Mr Towler:** I think that the affirmative procedure ought to be used for the first set of regulations.

[68] **Alun Davies:** You seem more guarded and cautious this morning, Mr Towler, with regard to your overall welcome for the proposed Measure than your written evidence would suggest. In your introduction to your written evidence, you welcome the opportunities set out in the proposed Measure. Perhaps it is the case that our questions have concentrated on areas where you have concerns, but in your responses this morning you seem more cautious and guarded in your overall welcome for it.

9.40 a.m.

[69] I find the tone of your response interesting. Our next witness is from the Wales Neurological Alliance, and from reading the evidence, it seems that he is similarly guarded. Do you believe that this proposed Measure could, potentially, do far more than it appears to be trying to do? You seem to be saying that there is almost a lack of ambition from the Government.

[70] **Mr Towler:** I do not want to be overdramatic about this, but we stand to have an opportunity taken away from us, and this is a great opportunity to get this right. If we take a look at figures in relation to the health needs of the UK, Wales has some of the most pressing, health-related problems in the UK. The role of carers in this country is under-recognised and not supported adequately. We have a great opportunity to change that. My concern, in advocating on behalf of young carers, is to ensure that they do not lose out. My fear about this at the moment is that they could lose out, and I do not understand the distinction between providing one thing in terms of information here and services and support in another piece of legislation over there. So, I am guarded about it. I was very pleased when I saw the LCO that dealt with carers, the debate that went on around it and where young carers sat in that, but I have become more guarded as this has proceeded.

[71] **Alun Davies:** You said in an answer to an earlier question that you were concerned that these issues would be covered by two pieces of Welsh legislation. Our next witnesses make the point that there is existing legislation that deals with carers, namely, the Carers (Equal Opportunities) Act 2004 and the Carers (Recognition and Services) Act 1995. Do you agree with what they are saying, in that we could be looking for consolidated legislation here that would create almost a charter of rights or opportunities for services for carers in Wales? That would unify existing UK legislation, which would obviously still operate in Wales, while, at

the same time, bringing together Welsh legislation.

[72] **Mr Towler:** There is an opportunity to do that and there is an interesting debate on rights and entitlements and what you should expect with regard to legislation, law, regulation and all the rest of it. The Welsh Assembly Government has given a very clear commitment regarding the UN Convention on the Rights of the Child, which is at the core of everything that this Government believes in. That is brilliant, and I applaud it every time I get the opportunity to do so, because I do not see that happening elsewhere in the UK. I said earlier that I wanted it to be watertight for young carers, and that is my ultimate concern. I have met and spoken with young people who have put some effort into establishing their rights and entitlements and into trying to raise our awareness, as adults, of what it is that they require. If, at the last stop, we manage to shoot ourselves in the foot by not really completing a process that would ensure that those children would get those rights and entitlements, then they are going to feel pretty poorly about us. I am concerned that we are not grasping the nettle sufficiently hard enough. We need the courage of our conviction to see this through.

[73] **Alun Davies:** I will just follow up on what you said about rights, because this is not about rights; it is about duties. Although the political approach has been to talk about carers' rights, the legislation does not provide carers with any rights at all; it provides public bodies with duties. Would you have preferred to have followed a more rights-based approach?

[74] **Mr Towler:** I am comfortable with duties being absolutely clearly identified for duty bearers. Everything that we take forward in relation to work with young people must be informed by a rights-based approach. That is the way to do it. In legislation, regulation and guidance, we must be very clear that we are committed to rights and entitlements, but it is always really helpful to identify the absolute duties that are incumbent upon organisations to deliver services for children and young people; in doing that, we ensure that rights are delivered. That is the way to go. We have to pin down what the responsibilities of duty bearers are, and sometimes we do not do that as well as we should. If we do that, it raises a big issue about inspection services and making sure that inspection focuses on delivery so that we narrow the gap between policy aspiration and delivery on the ground.

[75] **Leanne Wood:** I want to look at the question of consultation. Sections 2(1) and 4 of the proposed Measure give Welsh Ministers powers to make regulations to ensure that carers strategies set out how the relevant authorities will consult with carers. Will this enable young carers to influence planning and service development?

[76] **Mr Towler:** That goes back to my point that young carers are not on the face of the proposed Measure.

[77] **Leanne Wood:** They are not excluded either.

[78] **Mr Towler:** I take your point that they are not excluded, but they are not explicitly mentioned, and I still think that that is an important point. Article 12 of the UN convention makes it very clear that young people should have the right to voice their views on issues and decisions that will affect their lives, so this is consistent—as long as they are included—with article 12 of the UN convention. We need to ensure that we have services that are able to recognise that there are young people in a particular family who are young carers and have, therefore, an entitlement to be consulted. So, there is an issue about identification and assessment. Regulations for that will be key.

[79] There is also the issue of advocacy for young carers. Situations can arise where young carers would have a different view from that of adults in the family. Sometimes that can be sensitive. It is not something that would be that unusual, so the provision of advocacy support is important because young people will sometimes have things to say that might be at odds

with what is being said within the family. It does not mean that they are right or wrong, but somebody needs to listen to what those young people are saying so that they can do a full assessment. If I take your point that it does not mean that they are not excluded, the commitment to consultation is great and is very important, but there are a number of issues in relation to young carers that I have mentioned that we must not lose sight of.

[80] **Leanne Wood:** Voluntary organisations provide such advocacy services, do they not? Nothing will change on that front as a result of this proposed Measure, will it?

[81] **Mr Towler:** No, provided that, whatever the commissioning arrangements for the new service are, some young carers' services would still be providing those services. There would be a concern about whether those young carers' organisations that are currently funded to provide a service would continue to do so, but that is the life of commissioning services. As things stand, some organisations, like many voluntary organisations, would be worried about their futures. The commissioning of a particular service, or the specification for a new service, could sometimes be cheaper than, although perhaps not as comprehensive as, what is currently being provided by a particular young carers' organisation. Those are the localised issues that are bound to be raised. There is no doubt that the voluntary sector has a strong part to play, particularly in relation to advocacy for young carers, to ensure that young people get the support that they need and that their voices are heard in what can be—let us be honest—highly emotive family situations. It can be difficult for their voices to be heard when there is an argumentative or opinionated father, mother or elderly relative.

[82] **Leanne Wood:** Earlier on, you said that you welcome the move to consult carers, but there appears to be no provision in the proposed Measure to require the relevant authorities to take account of, or have regard to, any representations received from carers after a consultation exercise. Do you think that such a provision is needed in the proposed Measure?

9.50 a.m.

[83] **Mr Towler:** You would hope, would you not, that the word 'consultation' would suggest that you are asking for an opinion and would then listen to that opinion, make a decision based on whether you agree or disagree with it and then feed back to those who have taken part in the consultation that you have listened to them and have decided that they are right and that you are going to change something, or have decided that, although you understand the point, you are going to continue with the current situation. It must be more than a formality. We have become very used to the word 'consultation' in Wales and are quite poor at understanding fully what it means. I would not want it to be a rubber-stamp exercise. If young people or other carers have a clear view about something, then they have a right to a reply. It seems to me that we do not see that with some consultation methods.

[84] **Leanne Wood:** So, you do not necessarily have faith in general consultation processes. Therefore, would you like that to be included?

[85] **Mr Towler:** I would like to see that included. We need to have a common understanding about what consultation means. It is not just about asking a question, receiving a load of answers, ticking a box and saying, 'Thanks, we have consulted'. It is about asking the question, analysing the responses that come in, and providing a response to those who have taken the trouble to be involved in that consultation with the reasons why you are moving forward on something, why you have varied something, or why you will think again.

[86] **Leanne Wood:** Thanks for that. How confident are you that section 3 of the proposed Measure, the bit on appropriate information and advice, will ensure that the needs of young carers are met, particularly in relation to accessibility and availability?

[87] **Mr Towler:** A lot of that will depend on regulation. The key for me in relation to young carers is the word 'appropriate'. Information and advice for young carers needs to be in language that is understood by young people and it needs to be freely available. So, we have to think about where that information can be found. To go back to the point about stigma, it is important for young people to receive information about support that they could receive as a young carer by, for example, reading a poster or seeing a television advertisement and realising that it may relate to them. We need to be open in the way we provide that information and we need to think specifically about how young carers would receive that information. There is potential to address that wide spectrum. This relates to the question of how many young carers there are. Information is the key to all of this. They need to be confident that they can respond. So, it needs to be friendly towards them, it needs to be available in a number of formats and it needs to be clear. If you think that you are a young carer, there needs to be clear advice about what to do next. Perhaps that is quite distinct and different from the way in which we might provide information to adults in caring roles.

[88] **Mark Isherwood:** We have come to the final question of this session. You have highlighted concerns regarding the lack of training and support for young carers, specifically regarding the administration of medication, performing manual handling tasks and caring for those with mental health problems. Are you confident that the proposed Measure, as drafted, will allow regulations to address these issues? If not, how would you like to see this addressed?

[89] **Mr Towler:** It goes back to whether young carers are on the face of the proposed Measure. It seems that we are currently relying on the National Assembly for Wales (Legislative Competence) (Social Welfare and Other Fields) Order 2008 to make this happen. I would argue that, with regard to assessment and service delivery, not just advice and information, the way in which the proposed Measure is currently drafted means that young carers are in danger of falling outside the provision.

[90] As the children's commissioner, I was shocked during the preparation for the 'Full of Care' report to hear about very young children, aged nine or 10, giving injections to family members, lifting adults out of bed every morning and having no training in how to do that. They were complaining to me, at the age of 13, that their backs hurt because they had been doing that for the past four or five years. That shocked me. There is an absolute need for us, as a compassionate society, to ensure that our children and young people are getting the support, advice and training that they should have. I know that there is a question about whether they should be doing it at all but that is why I want to see young carers on the face of this proposed Measure. I want to ensure that children are getting those kinds of services. At the moment, they are not. It seems to me that breaches in the UN Convention on the Rights of the Child that we identified in 'Full of Care' could be resolved if young carers were on the face of this proposed Measure.

[91] **Mark Isherwood:** Do you have any closing remarks or are there any issues that we have missed that you would like to bring up?

[92] **Mr Towler:** No. I am sorry that I have been so grumpy this morning. I am not usually grumpy, but I have enjoyed the opportunity to be grumpy today.

[93] **Mark Isherwood:** I did not think that you were particularly grumpy. Thank you for your contribution. The only additional information referred to will be in the report, which we will access. A copy of the draft transcript of today's proceedings will be sent to you by the clerk for correction. Have a safe journey back to your office.

[94] **Mr Towler:** Thank you very much.

[95] **Mark Isherwood:** Our next and final evidence session this morning is with representatives from the Wales Neurological Alliance. I welcome you to the committee. Please introduce yourselves for the record.

[96] **Mr Carter:** I am Joseph Carter; I am from MS Society Cymru and I am also the vice chair of the Wales Neurological Alliance.

[97] **Ms Thomas-Wyllie:** My name is Carol Thomas-Wyllie and my day job is with the Motor Neurone Disease Association. I am also part of the Wales Neurological Alliance and I am a carer. So I am here in various capacities today.

[98] **Mark Isherwood:** Thank you very much. The paper that you have submitted has been circulated among Members, who have a series of questions for you. I will kick off with the first question. Do you believe that there is a need for this proposed Measure and do you support its overall aims?

[99] **Ms Thomas-Wyllie:** Yes, absolutely. We feel that carers are the essential component in both health and social care, but they seem to be the component that is often left out in most situations. They are often unrecognised and they do not have a clarified role to fulfil, although they are often the glue that keeps situations going in terms of care for either an adult or a child.

[100] **Mr Carter:** We endorse the aims of the legislation fully. It is very difficult to argue against it; it is a comparatively short enabling piece of legislation and certainly the Wales Neurological Alliance supported the LCO prior to this and gave evidence on that. However, we generally welcome this proposed Measure at the moment, although obviously the proof of the pudding is in the eating—in this case, the regulations that will follow.

[101] **Mark Isherwood:** I will now turn to Val to ask the next question.

[102] **Val Lloyd:** What will the proposed Measure allow that is not already provided for in existing legislation or by way of current practice?

[103] **Mr Carter:** The key element that will be allowed by this legislation is the provision to give the Welsh Ministers the power to compel local health boards and any health organisation to set up carers strategies.

10.00 a.m.

[104] As the explanatory memorandum states, there are already powers to enable Ministers to direct local authorities in this direction, but the key part, which is missing at the moment, is local health boards, or indeed, NHS trusts or any health organisation. This will give those powers to the Deputy Minister and allow her, or any future Minister, to bring both sectors together to put together the strategies.

[105] **Val Lloyd:** Turning to the scope of the proposed Measure, in your evidence, you comment on the fact that the proposed Measure would impose a duty to produce a carers' strategy on NHS bodies as well as local authorities. Do you agree that duties should be imposed on health and local government alike?

[106] **Ms Thomas-Wyllie:** Absolutely. At the present time, producing carers' strategies is a recognised component within local authorities, but the same is not true of the NHS, and that is a real omission. It is crucial that that should be the case.

[107] **Val Lloyd:** Further to that, you express concerns that the proposed Measure seeks

always to designate the lead authority as an NHS organisation, regardless of the circumstances. What are your reasons for making that statement?

[108] **Ms Thomas-Wyllie:** We realise that there is already a structure within local authorities with carers strategies that have been established over time. They have experience, therefore, of dealing with this issue, whereas the LHBs are newly formed and do not have a history in this area. It is just about ensuring that the knowledge and expertise is not lost.

[109] **Mr Carter:** I would add that there is real concern that good examples of best practice in local authorities will be lost if an NHS body or an LHB is designated as the lead organisation. Clearly, it is up to the Deputy Minister, through regulations, which organisation is the lead one. Our main comment on this matter is that the current proposed Measure, as drafted, restricts ministerial decisions on this in future. If the Deputy Minister were to choose a health organisation as the lead body in the first instance by regulation, we would comment on that and we would not see a problem with it in principle. With legislation being drafted as it is, however, the current or future Minister would have to amend the legislation to make a local authority the lead organisation, if she or he were to decide that local authorities are better placed to be the lead organisation.

[110] **Alun Davies:** Thank you for your written evidence, which I find among the most interesting that we have received so far to do with this proposed Measure. Would I be right in detecting a tone of disappointment running through your evidence?

[111] **Mr Carter:** I think that 'disappointment' is a strong term to use. We had a perception that this proposed Measure could have been so much more. We came before this committee just before Christmas to talk about the Proposed Social Care Charging (Wales) Measure, and in that instance, the legislative competence Order had given a very limited scope to the Assembly, and therefore the legislation, equally, had to be limited. Under this legislative competence Order, however, we feel that a wide power was given to the Assembly in the field of carers, but that this legislation seems to fall short of the maximum parameters that could be used. Although 'disappointment' is a harsh word, we did think that it could have been more encompassing and that more could be done.

[112] **Alun Davies:** Thank you for that. In your answer to question 6, you say that the Wales Neurological Alliance is disappointed by the narrow extent of the proposed Measure. In other parts of your evidence, you say that it is limiting the scope of what can be done. You also mention the opportunity for wider consolidation, and I think that other questions address that later. Where the scope of the proposed Measure is concerned, as it stands today, you say, in various parts of your evidence, that you believe that it could be much wider, and I think that you have said that, through regulation, it could be deeper in some ways. Can you explain to us again, and outline some of the things that you have said in your written evidence, how you believe the scope could or should be extended and how the regulations could be used to deepen the opportunities to provide services for carers?

[113] **Mr Carter:** There are two elements to that. With regard to the proposed Measure as it stands and how it could be broadened, the feeling of the Wales Neurological Alliance is that this is an opportunity, as you rightly pointed out, to consolidate legislation across the field of caring. If you look back at the history of carers' legislation, you will see that the Carers (Equal Opportunities) Act 2004 amended the Carers (Recognition and Services) Act 1995 and gave more provisions for carers to enhance their rights and responsibilities. We felt that this legislation could have added to that. In the previous evidence session, Keith Towler mentioned a primary charter of rights and responsibilities for carers. So, we feel that an opportunity has been missed to add to that in the legislation.

[114] The second point regarding regulation is that the proposed Measure could, via section

2, revolutionise how carers are consulted on the development of services for themselves and their loved ones.

[115] **Alun Davies:** Did you say ‘could’?

[116] **Mr Carter:** Yes, it could by regulations. Our comment in the response was that this is an area where we have to see what regulations come out of the proposed Measure. As drafted, if the Deputy Minister so wishes, it has the potential to revolutionise the level at which carers are involved in looking at, for example, specific services and centres of information for them and the person they care for. So, they could be involved at the maximum level and maximum interpretation of section 2. On the other hand, a more minimalist interpretation would be that that involvement would mean a letter being sent to them to ask for their views in the form of a survey. That area in particular is one where we have to see what the regulations look like. To enhance that section, we also proposed some basic minimum standards for what that consultation might look like. We did this for section 2(1)(c), where we proposed minimum standards on the face of the proposed Measure that a consultation may include, but would not be limited to, stakeholder meetings, surveys and the 28-day consultation period. That was to ensure that there was at least a minimum standard for this level of consultation, just to alleviate our fears that a future Minister might interpret the proposed Measure at the bare minimum of what is in front of us.

[117] **Alun Davies:** Thank you for that; that is very interesting and it is also an important point. Your evidence talks about carers’ rights—the term is used throughout your evidence. However, this is a piece of legislation that imposes duties on public bodies in relation to carers. Is that the right approach? You seem to say in your paper that you would prefer a more rights-based approach, if I have read it properly.

[118] **Mr Carter:** That is an interesting point; I had not considered it in that way prior to your asking the question. I think that the way that the proposed Measure has been drafted is correct, as it is clearly based on the Scottish legislation passed back in 2002. So, this is a form of words that has been used before. Rights need to be a part of it, and if you look at the previous carers’ legislation, albeit England and Wales legislation passed at Westminster, that was very much rights based. So, in attempting to resolve that, our feeling was that, rather than this being a standalone piece of legislation that would sit on a shelf with other carers’ legislation, it could repeal existing Westminster legislation for Wales and create a singular body of carers’ legislation that would encompass the rights elements of the previous legislation, perhaps enhanced, as well as the duties for the NHS and local authority bodies here. We felt that that would be a far more useful piece of legislation for carers, for people like us who work with carers, and for local authorities and health organisations. It would give them a better idea of how to interpret legislation, because it would be in one, consolidated, Welsh-specific place.

10.10 a.m.

[119] **Alun Davies:** With regard to the response of the Government, the Deputy Minister was clear in her evidence that she wanted the proposed Measure to address health bodies and the elements of local authority services that are concerned with the provision of social services rather than a wider approach. However, if you took a rights-based approach and looked at the individual, not the authorities and the public bodies, you would probably have included the full range of local government services, as the individual would have the right to receive services rather than duties being placed on the local authority. Are you comfortable with this approach as it stands?

[120] **Mr Carter:** Yes, we are comfortable with it as it stands. In the first instance, it appears to be the right approach to target social services departments and local health boards. There

might well be scope in the proposed Measure as it stands for the Deputy Minister to enhance this to cover housing departments, for example, at a later stage and we welcome that. However, these are the priority areas. Carers' strategies in local authorities mainly reside in the social services arena and the main reason that the proposed Measure has come about, as far as we are concerned, is to try to expand that to the local health board setting. So, I am comfortable with that at the moment.

[121] On the issue of rights versus duties, even if we were to have an all-encompassing piece of legislation that would talk about rights, looking at the Carers (Equal Opportunities) Act 2004, it would still need to have this duties element to it, because the legal element that is missing at the moment is the power for Welsh Ministers to compel local health boards or any NHS body to do this. So, even if the legislation consolidated the previous Acts, it would still need this duties element, otherwise it would essentially be a wish list. Welsh Ministers need the power to push local health boards in order to make these provisions possible.

[122] **Alun Davies:** That is an interesting response, because we started this session by discussing the limited scope of the proposed Measure and how it could do so much more. My perspective is that if you look at the Beecham process and the way that we have talked about the delivery of public services in Wales, you will see that we have always been citizen-centred—I say 'we', but I mean the Government—in terms of a philosophical approach. However, the proposed Measure moves—I am trying to avoid using the word 'back'—towards a different approach, which is about duties on public bodies rather than the citizen, as the individual who receives services, being at the centre and tailoring services to citizens' needs and that, therefore, the whole range of public services should be focused on the citizen rather than citizens simply taking from public bodies. Do you see the differentiation that I am trying to make?

[123] **Mr Carter:** Yes, I can see what you are trying to do there and that is an interesting interpretation. All that I can add is that, although the proposed Measure is about duties and pushing different organisations to provide strategies, one would assume from the explanatory memorandum that the strategies will be about the individual. However, in order to get to that place this power is needed to encourage bodies to put together strategies in the first place. That is our interpretation, but, equally, the point that I have raised before is that when we were talking about consolidating legislation and missed opportunities, we were talking about looking at a proposed Measure by amending the 2004 Act rights in the first instance. One would assume that a strategy would be based around what a citizen, or a carer, should expect.

[124] **Ms Thomas-Wyllie:** You said that the citizen receives the service. Often, in the current situation, it is the patient who receives the service but the carer features nowhere in that equation, certainly within the NHS at present. Within a local authority, the carer is perhaps a recognised component but, within the NHS, the carer often is not. So, the citizen is the patient, if you like, but the carer, particularly an informal carer, often does not have a recognised role at all and is not included as we would like that person to be seen. The carer is seen as someone who has responsibilities in caring for their loved one but no rights.

[125] **Alun Davies:** This legislation does not give them any additional rights, of course.

[126] **Ms Thomas-Wyllie:** Except that they would be recognised as an entity. Someone who is recognised as a carer then has recognition that they are performing that role, and there should be a strategy to enable, inform, and discuss with them, so that they would be a recognised component of the care package.

[127] **Darren Millar:** Your evidence makes reference to the inconsistencies that currently exist in Wales in the information available and the services provided to carers. I think that you refer to some examples: a help book of sorts for carers in Cardiff is 36 pages long, but similar

information provided in Anglesey is only five pages long. I do not know whether they are in a different typeface or whether it is the quality rather than the quantity that really matters, but there are clearly inconsistencies. Do you think that this proposed Measure, as it stands, will deliver consistency across Wales, given that the potential outcome could still be 22 different carers strategies—one for each local authority area?

[128] **Mr Carter:** Yes. I think that the proposed Measure, as drafted, will do that. It will depend on how stringent the regulations are. It would be a matter for the Deputy Minister, I suppose, to define how uniform they should be. The proposed Measure itself contains enough provisions for the Deputy Minister to sign off the strategies. So, one would expect there to be a more uniform standard of delivering the strategy. If a strategy is to work, it has to be based on what happens locally. If we are bringing together the various people and services provided in a local health board and in a local authority, they will be different in different parts of Wales. I would not imagine that every strategy would be word-for-word exactly the same, as that would mean that there was no local variety at all. However, we would certainly expect there to be a more uniform structure and standard to it.

[129] **Darren Millar:** Surely, the needs of carers in Anglesey and Cardiff are pretty similar, are they not? To play devil's advocate, because I believe in the local delivery of services, why should there be any difference between the information, support and advice provided to carers in Anglesey and that provided in Cardiff?

[130] **Ms Thomas-Wyllie:** I do not think that it is about the information, support and advice. I think that we would agree that everyone, wherever they live, should have access to that, and it should be a recognised component of the care of the person for the carer to be signposted to the advice, information and support required. The type of local services will vary in different places, between rural, semi-rural, or city-based services. They will be different. In some places, there will be community teams, for example, to which someone could be referred; in another place, that type of support would not be available. It is important for a carer to be signposted to local information. However, nowadays of course, instead of having a book produced in paper form, things are moving more towards having that information online, where it can be regularly updated. That is the other issue, as all this information needs to be up to date so that it is still valid for someone new coming along.

[131] **Darren Millar:** Mr Carter, you referred earlier to the use of regulations to try to get some consistency across Wales. As it stands, the regulations would be subject to the Assembly's negative procedure. Is that the right approach? You seemed to suggest in your evidence that the affirmative procedure should be followed.

10.20 a.m.

[132] **Mr Carter:** Our opinion is that the affirmative procedure should be followed. This proposed Measure is very much an enabling Measure—it is only five pages long. However, what could come out of that by regulation could make a real change to how carers across Wales are treated. So, yes, we feel that the affirmative procedure should be used in the first instance, and we are not alone in holding that view. For instance, while researching our evidence to put before you, we found that it has also been a long-held view of the Law Society in Wales, and we also found that the Subordinate Legislation Committee, now called the Constitution Affairs Committee, has held that view in respect of most of the legislation it has dealt with. So, we are not alone in that regard.

[133] We have spent the past two years watching and trying to assist the people in this building to draw down powers in the field of caring from Westminster, which we wanted and supported. However, our fear relates to the fact that we do not want to see legislation that immediately removes those powers from this building and gives them to Ministers, without at

least going through some sort of affirmative procedure. As I stated in our evidence and alluded to earlier, section 2 could be interpreted in a minimal or a maximal way. However it is interpreted will be a positive step for carers, but my personal belief and the alliance's belief is that it is only right for that to go through the Assembly first, although what comes out of that may differ considerably from what was originally anticipated by certain politicians.

[134] **Darren Millar:** I assume that you think that section 2 needs to be more explicit about the duties of local authorities and other relevant authorities, or about the hoops that they have to jump through in producing their strategies. You want more meat on the bone.

[135] **Mr Carter:** Of the proposed Measure, do you mean?

[136] **Darren Millar:** Yes, rather than just through regulation.

[137] **Mr Carter:** Yes, we would like that, and the reason is to provide at least a basic standard of consultation. Our fear is that that consultation exercise could amount to as little as a letter. On the other hand, at its more maximal interpretation, regulation could specify that there must be an all-encompassing community poll of sorts, with stakeholder reference groups and public meetings. However, that is currently up to regulation. Our suggested amendment is to allow this committee, perhaps later down the line at Stage 2, to include a minimum standard in the proposed Measure, so that if all this goes through the negative procedure as proposed, at least there will be a minimum standard for the consultation.

[138] **Leanne Wood:** You mentioned your suggested amendment for the minimum standard of consultation to be put on the face of the proposed Measure. What are the benefits of specifying a minimum standard of consultation?

[139] **Mr Carter:** The obvious benefit is that it would ensure that the current Deputy Minister or any future Minister would bring forward regulations that meet those bare-minimum standards. Our fear, particularly in the current climate, is that, once this has been passed, and after the general election that is to be held shortly and the Assembly elections in 2011, any future consultation may not be viewed as so much of a priority as it would be if it were to be included on the face of the proposed Measure.

[140] Our suggested amendment was really intended to ensure a basic level of consultation and, as part of that, we discuss an amendment specifying the voluntary action groups locally, because they are a key element that will have to be a part of this consultation. If the proposed Measure relies almost entirely on the negative procedure rather than the affirmative, there would be no standards at all to fall back on.

[141] **Leanne Wood:** There appears to be no provision in the proposed Measure to require the relevant authorities to take account of representations from carers following the consultation. How confident are you that the proposed Measure, as drafted, will ensure that their voices are listened to and acted on?

[142] **Mr Carter:** I am afraid that we will have to wait and see with this particular example. We hope that future regulations will address that but, without seeing them, I am unable to comment either way. Having heard the Deputy Minister speak in Plenary about this, and having read the explanatory memorandum, one would expect that to be the case, but it is not that obvious in the proposed Measure as it stands.

[143] **Leanne Wood:** Would you include it on the face of the proposed Measure in that case?

[144] **Mr Carter:** Yes, I think so. It is not something that we picked up to any great degree but, yes, I think that that would be beneficial.

[145] **Leanne Wood:** Thanks for that. Local authorities and health boards no longer have matching boundaries: there are 22 local authorities and seven local health boards. Do you anticipate any problems arising when working jointly on the production of the strategies, and with regard to how the relevant authorities engage with the local groups?

[146] **Mr Carter:** Yes. Unfortunately, we fear that there could be a problem there. This is one element that I am most curious about as regards the regulations. As we understand it, there are two options available to the Deputy Minister: either there will be seven strategies, with local authorities working together as you suggested, or there will be 22 strategies with the local health boards having to work on as many as six of them, in the case of north Wales. Clearly, that would not be a good use of their resources. This is an ongoing issue, not just for this proposed Measure, but for most joint working since the reorganisation in October 2009. I am curious to see how it will work. If the strategy is to be relevant to people on the ground, we would have thought that it would be most useful to have 22 strategies. After a person is discharged from hospital, most of the care support services are provided by the local authority, and that is partly why we are sceptical about making the NHS body the lead. That is where the good practice currently is. On the other hand, if you go for the LHB-based model, local authorities would have duplicate strategies. It is a difficult one, and I am curious to see how the Deputy Minister resolves it. It is an issue here, and it will be an issue with any joint working following the reorganisation.

[147] **Leanne Wood:** In your evidence, you say that many young carers do not understand that they are carers and assume that their work is a part of the wider role of being a husband, wife, son, daughter, mother or father. This group is often given little or no information about the services and support available to them. Does the proposed Measure ensure that the information and advice provided to carers generally will be sufficiently accessible to this group of new carers and address their particular needs?

[148] **Ms Thomas-Wyllie:** It is a big issue for people who find themselves in a situation in which perhaps a loved one is diagnosed with something, but where no-one says, 'You are now a carer'. People often simply assume the roles, but it is never recognised and they are not perceived as providing that care. It is important for that to be identified, especially within the health service, and for people to be labelled, almost.

10.30 a.m.

[149] They are given that identity so that they can be signposted to any information and support available. At the moment, that usually happens within social care. As we have said, there are examples of good practice, and that is usually a situation where this is picked up. However, there is no history of that within LHBs, within the hospital service, and that is a very big element. Speaking from personal experience, I cared for my dad who had Parkinson's disease. Sadly, he died last April and, since then, I have been caring for my mum who has Alzheimer's. When I go to hospital appointments, it is only the doctors I know personally who will ask, 'Are you okay? How are you doing?'. The caring role is not taken on by anyone else; it is not recognised. Certainly, no-one has ever signposted me to information. I am capable of finding it for myself because I know something about these conditions, but other people would not be linked in.

[150] **Leanne Wood:** What if people do not want to be labelled as a carer?

[151] **Ms Thomas-Wyllie:** That is fine. However, they need to have access to and be offered the support. They do not have to have a label in that sense, but with regard to how they are perceived, there should be that recognition. I suppose I meant 'recognition' by the word 'label'. So, it is not a case of saying, 'You're a carer and therefore your role is different'.

What you are saying is, ‘You have that role and, therefore, you should have access to the benefits, support, written information, helplines and the other things that are available to people in that role, which are not written down, particularly within the NHS where there is less awareness’.

[152] **Leanne Wood:** So, if someone is identified as having an illness or a need that requires care, should there be some sort of system in the health service that means that they are automatically asked, ‘Who provides your care?’, and, ‘Can we speak to them about their potential needs?’?

[153] **Ms Thomas-Wyllie:** Yes, absolutely.

[154] **Leanne Wood:** So, that does not happen at the moment.

[155] **Ms Thomas-Wyllie:** No, it does not happen at all. Often, it is not recognised that a person is providing care and therefore they may well be excluded from conversations. So, they will not be party to information about that person’s condition, which will be treated as confidential, between the patient, in this case, and the doctor. That is fine, but it has implications for the person who is providing the care. So, if they are not recognised in that way—that is what I meant by ‘labelled’, although it was the wrong term—it is not understood that they should form part of any forward planning for care, undergoing surgery or some sort of intervention that would make a difference to the caring role that the person is undertaking. However, they are not even part of the conversation. They are just expected to cope and to pick up the pieces. We have a whole army of people in Wales—adults and young carers—providing informal care. Without them, our whole system would grind to a halt. In this new century and new decade, we really have to get the support for carers right.

[156] **Mark Isherwood:** Thank you. We have come to the final two questions, which I will ask. In your written evidence—and I think that you, Joseph, referred to this at the beginning of your oral evidence today—you referred to the opportunity that the proposed Measure presents to consolidate carers’ legislation. As currently drafted, carers have to consult three different pieces of legislation. How would the inclusion of the existing Acts in the proposed Measure improve the position of carers?

[157] **Mr Carter:** With regard to improving the position of carers, having everything in one place would make it far easier for them to understand their rights. Realistically, the improvement would not be seen so much by carers directly, although they would see it indirectly. It would have a more direct impact on local authorities and local health boards, which have to interpret how legislation affects them. If everything was in one place, it would be far easier for them to provide services for carers. So, carers would see the benefits indirectly rather than directly.

[158] It is also a matter of principle with regard to how law in Wales is working, or should be working. At the moment, we have a system whereby proposed Measures go through the Assembly, making small amendments to existing England and Wales legislation, rather than taking a piece of legislation for England and Wales and restating the text in a Welsh context. Last year, in the case of the Proposed Social Care Charges (Wales) Measure, that was not possible, as the powers that you were given were restricted by the competence Order. However, the LCO that relates to this proposed Measure gave Ministers the power to bring legislation forward, and so there was an opportunity here to simplify the legislation. It is more about the concern in respect of creating bad law and how that will affect how the officials in local health boards and local authorities interpret it, rather than about the direct effect that it would have on carers on the ground.

[159] **Ms Thomas-Wyllie:** It is also about clarity. When they are undertaking a caring role,

people are often not in a position to think about themselves, and they require someone to understand that situation and to tell to them that they are entitled to a carers' assessment, for example. Most of the people I meet through the Motor Neurone Disease Association have never been signposted in that direction. It is sad to think that a carer has perhaps undertaken that role for years, and that no-one has looked at providing support for them. The more that everything is in one place, the more transparent it is, and it is then clearer what someone is entitled to and what they should receive. That can then be signposted and they can be enabled to take that forward. Nowadays, you perhaps have to seek it. It is fine if you are articulate and can deal with bureaucracy—although, even then, it is daunting to try to fill in some of the forms—but it is very difficult for people who do not have that sort of backing. We, as an alliance, would like to see that it is not dependent on the individual carer seeking the assistance, as the structure should be underpinned, and anyone fulfilling that role should come within that supportive framework.

[160] **Mark Isherwood:** Finally, are there any sections in the proposed Measure, other than those already addressed this morning, that you feel could be improved upon or clarified?

[161] **Mr Carter:** I think that we have had a full and frank conversation already about most of the sections. The only thing that I would bring to the committee's attention, which was in the written evidence, is our query as to whether the proposed Measure, as written, needs to be amended to make reference to the Local Authority Social Services Act 1970. That is a query for your legal officers. Our reasoning for saying that that amendment might be necessary is that previous carers' legislation made amendments to that Act. Duties are created for local authorities and health bodies in the proposed Measure. So, it was our view that there might be a need for that section to tidy the law up in this area. Clearly, that is a matter for your officials, as they know more than we do about that section.

[162] **Mark Isherwood:** I think that that is fair.

[163] **Mr Carter:** Absolutely.

[164] **Mark Isherwood:** Do you have any closing remarks to make before we bring the session to an end?

[165] **Ms Thomas-Wyllie:** From the perspective of a carer, it would be marvellous to see this legislation going through and the lot of carers being improved in the coming years. That would be a wonderful legacy for this place.

[166] **Mark Isherwood:** You will be sent a draft transcript of today's proceedings by the clerk for correction if necessary before a final version is published. Therefore, it just falls to me to thank you both for being with us this morning and to wish you a safe journey.

10.39 a.m.

Dyddiad y Cyfarfod Nesaf Date of Next Meeting

[167] **Mark Isherwood:** I ask Members to note that the next meeting of the committee is on Wednesday, 3 March at 9 a.m.. We will be taking evidence from the Welsh NHS Confederation, the Welsh Local Government Association, Carers Wales and the Wales Carers Alliance.

10.40 a.m.

Cynnig Trefniadol
Procedural Motion

[168] **Mark Isherwood:** I move that

the committee resolves to exclude the public from the remainder of the meeting in accordance with Standing Order No. 10.37(vi).

Derbyniwyd y cynnig.

Motion agreed.

Daeth rhan gyhoeddus y cyfarfod i ben am 10.40 a.m.

The public part of the meeting ended at 10.40 a.m.