



Cynulliad Cenedlaethol Cymru The National Assembly for Wales

Y Pwyllgor Deisebau The Petitions Committee

**Dydd Mawrth, 16 Gorffennaf 2013
Tuesday, 16 July 2013**

Cynnwys Contents

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

P-04-456 Dementia—Gallai Hyn Ddigwydd i Chi
P-04-456 Dementia—This Could Happen to You

Deisebau Newydd
New Petitions

Y Wybodaeth Ddiweddaraf am Ddeisebau Blaenorol
Updates to Previous Petitions

P-04-452 Hawliau Cyfartal i Bobl Ifanc Tiwb-borthedig—Sesiwn Dystiolaeth
P-04-452 Equal Rights for Tube-fed Youngsters—Evidence Session

P-04-452 Hawliau Cyfartal i Bobl Ifanc Tiwb-borthedig—Trafod y Sesiwn Dystiolaeth
P-04-452 Equal Rights for Tube-fed Youngsters—Discussion of Evidence Session

Cofnodir y trafodion yn yr iaith y llefarwyd hwy ynndi yn y pwyllgor. Yn ogystal, cynhwysir trawsgrifiad o'r cyfieithu ar y pryd.

The proceedings are reported in the language in which they were spoken in the committee. In

addition, a transcription of the simultaneous interpretation is included.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Russell George	Ceidwadwyr Cymreig Welsh Conservatives
Bethan Jenkins	Plaid Cymru The Party of Wales
William Powell	Democratiaid Rhyddfrydol Cymru (Cadeirydd y Pwyllgor) Welsh Liberal Democrats (Committee Chair)
Joyce Watson	Llafur Labour

Eraill yn bresennol
Others in attendance

Dr Tymandra Blewett-Silcock	Prif Ddeisebydd Lead Petitioner
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Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol
National Assembly for Wales officials in attendance

Kayleigh Driscoll	Dirprwy Glerc Deputy Clerk
Siân Giddins	Dirprwy Glerc Deputy Clerk
Helen Roberts	Cynghorydd Cyfreithiol Legal Adviser
Naomi Stocks	Clerc Clerk
Phillippa Watkins	Y Gwasanaeth Ymchwil Research Service

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] **William Powell:** Bore da, bawb. Good morning, all. Welcome to the final Petitions Committee meeting of the summer term. We have no apologies this morning; I believe that we will shortly be joined by our colleague Joyce Watson. Normal housekeeping arrangements apply and we will get on with our agenda items this morning.

9.04 a.m.

P-04-456 Dementia—Gallai Hyn Ddigwydd i Chi
P-04-456 Dementia—This Could Happen to You

[2] **William Powell:** The first item is the consideration of the evidence that we took at our last meeting from Helen Jones and her team on dementia. This is petition P-04-456 Dementia—This Could Happen to you. I think that you will agree that we had a really useful session with all three: Helen Jones, the lead petitioner, and her colleagues. Good morning,

Joyce. We have the transcript available as an aide-mémoire. Are there any initial thoughts on the best way forward? Obviously, we now have the Wales Audit Office report, as well as the correspondence from the Minister, and, indeed, from the Auditor General for Wales, which is helpful in setting the whole thing in context. Russell, do you have any initial thoughts on the best way forward and on any particular aspects that struck you during the evidence session?

[3] **Russell George:** I thought that it was a very useful session, and I thought that it was extremely useful for the lady who was giving evidence—the main petitioner—to give us her experience. I thought that it was one of the most useful evidence sessions that we have had. I am open to how we take this forward, listening to other Members' views. I think that the initial step would be that we would write to the Minister for Health and Social Services. That is our normal protocol, so we should do that to start with, in any case.

[4] **William Powell:** In the light of the report that we now have, and the correspondence that we have received from Mark Drakeford, I think that we should definitely write to the Minister for Health and Social Services again, highlighting some of the key points that have come up during the session, particularly looking at some assurance that the petitioners will be actively involved as part of the stakeholder group to take these issues forward in developing the framework. I believe that the Minister is quite candid in his response, and quite open to the fact that things are not as they should be. That ties in with the Wales Audit Office report, which, in its three summary recommendations, is pretty clear; I know that it does not say that it had seen any evidence of budgets playing a role, but I think that, in all other respects, it sort of supports some of the key elements of what the petitioners have been suggesting all along.

[5] **Joyce Watson:** There have been quite a few things. Ann Clwyd, for instance, is doing a piece of work on care for patients, and I am sure that, when that is completed, other bits of evidence might come out. I am not sure whether she is looking at people in Wales. There is also the work of the Commissioner for Older People in Wales. However, I found the session to be an illuminating piece of work that we have done.

[6] **William Powell:** Yes, it was a powerful session, was it not?

[7] **Joyce Watson:** As you say, it is about taking it forward as best we can. This issue straddles health and social care, quite frankly. I assume that we will at least send our findings to the Health and Social Care Committee. Are they separate? Health is one committee, and social care—

[8] **Ms Stocks:** It is one committee.

[9] **William Powell:** It is all integrated under David Rees now, as the new Chair of that committee.

[10] **Joyce Watson:** There are elements of social care that come into local government—that is what I was thinking. There are quite a few elements of it that come in there. However, we must certainly take it forward—we cannot just leave it where it is. I certainly found it a useful session.

[11] **William Powell:** I would be very happy, on behalf of the committee, to write along these lines, particularly emphasising the importance of Helen Jones and her fellow petitioners being really engaged in this. I thought that the balance of the team that she brought with her that day was part of what made it such a successful session. Therefore, I will ensure that that happens, and happens within good time, as we move towards recess. Thank you very much indeed for that. We will now move on—

[12] **Joyce Watson:** Before we move on, may I ask whether it is the case that the Children

and Young People Committee cannot do anything else with this? Are we going to try to slot it in? Can we do that? We are going to take it forward, are we not?

[13] **William Powell:** In the light of the discussion that we have just had, I intend to write to the Minister for Health and Social Services. Potentially, it could be of use to copy in the new Chair of the Health and Social Care Committee, David Rees, particularly in the context that he comes new to that role, to keep him abreast of developments. I do not think that we were asking at this stage for the committee to take anything forward just yet, but it may well be that that will be suitable at a future time. However, it would be useful to make sure that we had a belt-and-braces approach. Are you happy to do that? I see that you are.

9.10 a.m.

Deisebau Newydd New Petitions

[14] **William Powell:** The first of the new petitions is petition P-04-494, Robotic assisted laparoscopic prostatectomy must be made available to men in Wales now. This petition was submitted by Professor Kevin Davies MBE, and it collected 2,090 signatures. There will be a presentation tomorrow lunch time, which I hope that you will be able to attend, by Professor Davies and some of his fellow petitioners. The text of the petition reads as follows:

[15] ‘Robotic assisted laparoscopic prostatectomy is the 21st Century Gold standard. Wales as a nation must be at the forefront in offering this standard. We, the undersigned, are appalled by the fact that men in Wales with prostate cancer cannot be offered robotic surgery in Wales, yet in England ALL men have this choice with at least 40 locations offering this treatment and with men from Wales having to pay thousands of pounds to access this capability in these English NHS facilities (typically between £13-15,000). Clearly, many men in Wales cannot afford this. We call on the National Assembly for Wales to urge the Welsh Government together with the National Health Service of Wales to resolve this totally unfair predicament and serious lack of essential resource within our NHS in Wales without delay. It is vital that this technology, this 21st Century Gold Standard is offered to men in Wales. It simply cannot be right that such technology is available elsewhere and that men from Wales have to pay to avail themselves of it in an NHS facility in England.’

[16] I apologise for the length of delivery there. As yet, we have not undertaken anything in relation to this petition. It is interesting that, again, we see a sort of cross-border comparison on health entitlements coming to the fore, as was the case in relation to the dementia petition, but in a very different field. I think that, at this stage, the first and only thing that we should probably do is to write to the Minister for Health and Social Services to seek his views on the petition. We also have a valuable opportunity tomorrow lunch time to engage with the petitioner and to hear some more details, and possibly some personal testimony around these issues.

[17] **Joyce Watson:** I agree that we write to the Minister for Health and Social Services, but I would also write to all the local health boards, because the delivery is actually down to them, to see what they have to say. So, we will have done both.

[18] **William Powell:** I would be happy to do that, particularly in the context of the time lag now in our consideration. I suppose that that would gather a better body of response than writing purely to the Minister. Excellent. Do any colleagues wish to add anything?

[19] **Bethan Jenkins:** I have met with Cancer Research UK, which has done some work on new treatments. I know that it is difficult to engage with all of the charities, but I was

thinking of how we can flag it up on the website, potentially, that we have certain petitions. There might be some groups that are interested in perhaps giving us evidence or just saying a bit about what they already do. That might give us more knowledge. Even if the Research Service provided us with bullet points on some of the charities that do some work on this, that might help us.

[20] **William Powell:** Perhaps we could commission a short, focused research piece on this. I think that that would also bring something, as you say. We would then be better placed to take it forward properly again in the autumn, and perhaps during some of our summer engagement activities, which we will mention later in the meeting, where there will be an opportunity for some people who are active in this field. This has in excess of 2,000 signatories. Potentially, we may have the opportunity to meet people as we are out and about at the Royal Welsh Show, the Eisteddfod and elsewhere. I am happy to take that on board and write to the local health boards and, as originally suggested, to the Minister for Health and Social Services.

9.15 a.m.

[21] The second of the two new petitions is P-04-495, Stop People Trafficking & Slavery in Wales. This petition was submitted by Ignite/Big Ideas and collected 1,523 signatures. It has a much shorter text:

[22] ‘We call upon the National Assembly for Wales to urge the Welsh Government to do all within its power to make Wales free from the illegal activity of people trafficking and slavery.’

[23] The group is coming to meet us today on the steps of the Senedd at 1 p.m., and I hope that colleagues will be present to hear directly from some of the activists about this particular petition. I am happy to write to the Minister for local government on this, seeking her views on the petition, and also in her role as the overarching manager of Government business. Joyce, I know that you have been particularly active in this field. Can you share any thoughts that you might have at this moment?

[24] **Joyce Watson:** Yes, I have been somewhat active. I will be interested to hear what they have to say this afternoon. What we could do—or, certainly, I could immediately write back and say what the Welsh Government is doing. I do not know whether they are fully aware of all the aspects of the Government’s commitment to preventing people trafficking and slavery in Wales. It would be fantastic if we could stop it, like many other things, but that is a huge ask. The Government is very much committed to this issue, and we have an all-Wales trafficking co-ordinator, the only one of its kind in the UK. I have also been engaged in a British-Irish parliamentary piece of work that will be out in October, asking for much the same across—

[25] **William Powell:** That report is due out in October. I was going to mention it.

[26] **Joyce Watson:** The foundation of that looks to Wales as the best example.

[27] There are many aspects to this issue, of course. The criminal aspect is not devolved. We do not have any jurisdiction over policing, international relations and many other aspects, but we do have over looking after people, especially children under the United Nations Convention on the Rights of the Child, and we expect local authorities and others to take their part in ensuring that those actions happen. The Welsh Government funds BAWSO—Black Association of Women Step Out Ltd—to look after women and their children who have no recourse to public funds. So, there is an awful lot, and I am happy to write so that they are fully apprised of what we are doing, both here in Cardiff and in north Wales, and with the

trafficking co-ordinator, in the fields that we have jurisdiction over. The problem here is where we have jurisdiction and how we work with partners when we do not have it.

[28] There is also Parliamentarians Against Human Trafficking, in which I have been engaged. It comprises parliamentarians in the UK, Ireland and Europe who have all signed up to try to do something about trafficking across the borders, both nationally and within the European Union. I will not go on, because I could all day about trafficking, but I think that it would be fair for me to write as the chair of the all-party group on trafficking, putting a précis together, at least, to give to the petitioners and for them to consider it while we write to the Minister.

[29] **William Powell:** I am conscious that this is the first consideration, but this will definitely be something that we can take forward in discussion later today, and I suspect that this is one that may be appropriate for an evidence session or for us to draw on some of these other aspects. That is probably for when we revisit the petition. That is really helpful.

[30] **Joyce Watson:** I can be your expert witness.

[31] **William Powell:** We will look forward to your contribution as ever.

[32] **Bethan Jenkins:** I think that that is comprehensive. I would like to have an update on the anti-trafficking co-ordinator. I find it difficult sometimes to get access to information, but I appreciate all of the work that others have done on this.

[33] **William Powell:** Excellent. We will look forward to our fuller consideration of this when we return, with the benefit of this correspondence and other things in the autumn.

9.20 a.m.

Y Wybodaeth Ddiweddaraf am Ddeisebau Blaenorol Updates to Previous Petitions

[34] **William Powell:** First of all, we have P-04-483, A plain English /Cymraeg clir policy for all Welsh Assembly and Government communications. This is one of a suite of petitions that has been submitted by Sovereign Wales. It was initially submitted in May of this year with the support of 450 signatures, calling on—sorry, I thought that that was more than I had recalled; there was a typo on one of my papers. It was actually 11 signatures, but no less valuable for that.

[35] We have quite a significant body of correspondence that we have received back. We have a detailed response from the First Minister, and quite a significant body of papers from Claire Clancy here within the Assembly. We also have the style guide, which has been supplied by Iwan Williams. That makes for some very interesting reading, some of it really quite complex, such as issues around gender neutral drafting of legislation and so on. It is a full response, and I hope that Sovereign Wales as an organisation will be interested in some of what has come forward. How do colleagues want to play this one? There are clearly some important underlying issues in terms of plain language and remaining as accessible and understandable as possible.

[36] **Russell George:** I think that a lot of the general public across Wales would be interested in this petition. I think that it is one that chimes with a lot of people. I am just wondering whether it would be useful for us to have an evidence session on this. Perhaps it is something that the committee could explore over the summer recess.

[37] I heard on the radio news as I was travelling down this week that there was an advertisement for the job of bus conductor and that the Plain English Campaign had criticised the language used for ‘a public-facing communicator’, and it went on. The campaign thought that it surely should have just said ‘bus conductor’. People were responding to that by just agreeing that it was ridiculous.

[38] I think that this is something that is of wider interest, to people other than the petitioners who have put this forward. I think that it would be useful if we could schedule in an evidence session sometime in the autumn term.

[39] **William Powell:** I think that that might well have some merit. I think that we should also probably cast the net a little bit wider. We have some really good information and resource material here from the Assembly and from Welsh Government. Possibly, it is time to open it out a little. We have, for example, the Plain English Campaign that we could be in touch with. There is also the Cymraeg Clir unit at Canolfan Bedwyr, which might be a useful centre to engage with, so that we get perspectives from both of those. In thinking about moving to an evidence session in the autumn term, I suppose that we should write to them in the first instance to get their take on it, and then think about who we would want at the table. Clearly, the petitioner body of Sovereign Wales seems to be an engine, almost a think tank, of different issues that it brings to us. It would be interesting to give it the opportunity of contributing more directly.

[40] **Russell George:** I think that it would only be worth having a session if we had a number of the relevant bodies mentioned in.

[41] **William Powell:** Potentially, as I said, the Plain English Campaign and the Cymraeg Clir unit could bring us a perspective there, which could be useful.

[42] **Bethan Jenkins:** I would rather wait to see what the petitioners think of the documents first. I appreciate that it is an important issue, but, if we have these two comprehensive documents, and that is what the Assembly and the Government are basing their work on, I do not want to take evidence on something that perhaps—

[43] **William Powell:** You are suggesting that we get a considered response from Sovereign Wales.

[44] **Bethan Jenkins:** Yes, because, for me, it is about more than having plain language; it is about how you communicate that document or that legislation in other ways. For example, since the Kidney Wales opt-in legislation, I have had people say to me that they did not know about any consultation. So, I think that it goes wider than just having plain language; I think that it is about the whole mix and accessibility. I know that is not in the wording of the petition, but I think that we have to look at it in that mix. If you use acronyms all the time, or Cardiff-bay-bubble speak all the time, nobody understands that, and I can appreciate that, but I suppose that that is more to do with training politicians and training charities to try to normalise the language that they use so that people can understand what they are saying.

[45] **William Powell:** So that we are not creating unnecessary barriers.

[46] **Bethan Jenkins:** Exactly.

[47] **William Powell:** We have had an initial response from the petitioner, have we not?

[48] **Bethan Jenkins:** Oh, right.

[49] **William Powell:** I will just refresh my memory. Yes, there has been an initial

response, but maybe there would be an opportunity for a more considered and fuller appraisal of that. If we get such a response from the petitioner, I think that there is possibly an appetite to broaden this out a little and take it forward in an evidence session.

[50] **Russell George:** I am happy with what Bethan has suggested, but rather than waiting to come back to the committee after the recess, which is some time away, can we leave it to your discretion, with the committee clerks, if the petitioners do come back, to take that forward if you feel that is right?

[51] **William Powell:** I am certainly happy to follow up with the petitioner and to write to both the Plain English Campaign and the Cymraeg Clir unit at Canolfan Bedwyr, as I said earlier, to scope this out. I think that broadening it out a little would make a lot of sense.

[52] **Bethan Jenkins:** It is relevant to disability groups as well, is it not, and young people, how we use language appropriately and how we have all of the tools necessary for everybody to engage with us, so that we do not discriminate in terms of how people can access us?

[53] **William Powell:** It is also really important that we go out and about, as we are planning to do later this summer. That is all part of the wider strategy, I think, is it not? Excellent; we will take that forward as agreed.

[54] We will move on now to petition P-04-362, Ambulance Services in Monmouth. The petition was submitted by Mathew Davies in February of last year and collected 450 signatures. As you recall, we last considered this in June and we wrote to the Minister, and, indeed, back to the petitioner. We have responses from both, and we recently had the ministerial update in Plenary on 9 July, which was an initial response to the McClelland review on the ambulance service.

[55] In his response, the petitioner is very clear that he would like to have the opportunity of a scrutiny session and of contributing to that in the Health and Social Care Committee. I know that there is some lack of clarity about that committee's forward work programme; it has a lot on and it has just recently finished a substantial body of work around human transplantation, as we know. If colleagues are agreeable, I will write to David Rees, the new Chair of that committee, forwarding correspondence from the petitioner, with a request for some clarity on its forward work programme. Clearly, a lot of the wider issues have been addressed by McClelland, but the petitioner is evidently keen that this is taken forward and he sees the Health and Social Care Committee as a key route to doing that. If I write to the Chair making that point, then we can take the matter forward.

9.30 a.m.

[56] **Bethan Jenkins:** May I make a point about process? I do not know whether this is something for the Business Committee, but we refer a lot of petitions to committees and they often come back saying that they do not have the time. I appreciate that legislation is happening. Could there be a way, because we are trying to be forward-facing as an institution, in a private meeting, for AMs to agree to a forward work plan and for a temporary work plan to be put on the website to show society and the citizens what it is? I think that people are very confused about how things are decided. That would perhaps allow people to understand why a committee would not be able to take on a new inquiry and so we would be managing expectations. We are going to get issues such as this all the time—

[57] **William Powell:** Increasingly so, with the whole logjam of legislation.

[58] **Bethan Jenkins:** Yes. Legislation will be the reason why they cannot discuss it, so

we have to look for alternative options for people as well. I do not know what is possible, but we could at least throw it into the mix and ask the Business Committee to consider something along those lines and how it could look to conduct some sort of a consultation as to how—

[59] **William Powell:** I suppose, in a way, that that picks up this idea of openness and being communicative that arose in the conversation on the previous petition.

[60] **Bethan Jenkins:** It is just that it is cropping up quite a lot at the moment. I think that it would help people understand how the Assembly works.

[61] **William Powell:** I would be happy to work with the team to raise that back up the food chain and see whether we can get a little bit more clarity or transparency about the way in which we do our business. Thanks, Bethan.

[62] Moving to P-04-343, Prevent the destruction of amenities on common land—Anglesey, this petition was submitted by J.E. Futter in November 2011 and had the support, at that stage, of 156 signatures. It calls on

[63] ‘the Welsh Government to examine ways to prevent the destruction of amenities on common land, including for example the Marian Common in Llangoed, Ynys Môn.’

[64] We last considered this back in April and we wrote to Anglesey council. We have its response, along with further information from the petitioners. There is the possibility that we could incorporate a site visit to this particular piece of common land in the forthcoming visit that is being shaped up at the moment. That is something for colleagues to consider. I do not know whether the Petitions Committee has ever been to Ynys Môn—I suspect not. Given the body of corporate memory between the clerk and Bethan, you would recall that. So, that could be a first and it may be an appropriate one for us to build in. What do colleagues think?

[65] **Joyce Watson:** I am quite happy to go to Ynys Môn. I have been there a few times, so it will not be a first for me. If we are in the area, we might as well incorporate it, if it is possible and feasible and everything else. As long as we take good walking boots and waterproofs, I am sure that we will all be fine. I would certainly support that.

[66] **William Powell:** I would be happy to write to the Minister for Culture and Sport highlighting the difficulties that the petitioners have flagged up in terms of bringing forward protection for common land that they feel is under threat.

[67] **Bethan Jenkins:** Is common land an issue for the Minister for sport?

[68] **William Powell:** I understand that it is. It is a quirk of the—

[69] **Bethan Jenkins:** I ask only because I have been doing stuff on common land in relation to opencast mining and things, and I have been told to raise that for the planning Bill. So, I am wondering whether that is something that we can look at. I did not know that it was—

[70] **William Powell:** There are some interesting quirks, are there not, in relation to the allocation of the portfolios? However, I think that it does sit under that portfolio.

[71] **Ms Stocks:** My understanding is that that is where it sits, but we can double check that.

[72] **William Powell:** I did query it when we had a previous discussion.

[73] **Bethan Jenkins:** I am not doubting it, I am just curious, because, with regard to the planning Bill and any potential changes, commoners' rights might be different in this regard. If they do fit into potential changes in the planning Bill, we can let the petitioners know. If they do not, then, obviously, we can go to the Minister for sport.

[74] **William Powell:** Yes. I am happy to do that, and I think that we have an amber to green light to proceed with putting this into our itinerary for the autumn visit. Good.

[75] We now move to P-04-385, Petition regarding balloon and lantern releases. This was submitted by Bryony Bromley in May 2012 and has the support of 564 signatures. Of course, this has become particularly topical in light of the disaster at Smethwick, which could have been so much worse had it not been for the intervention of the fire service and its colleagues in bringing that blaze under control. I am sure that we would all register our appreciation of what they did on that occasion, just as they do every day of the week.

[76] We last considered this petition in June, and we wrote to the Minister, and we have a response in our public papers, along with further information from Bryony Bromley. Also, interestingly, in responding to a recent question in Plenary, the Minister for Local Government and Government Business stated that Alun Davies, the Minister for Natural Resources and Food, will shortly be issuing a written statement on these matters. So, it might not do any harm for us to write to Alun Davies asking whether there has been any development in the Government's approach following the recent Smethwick fire. Are colleagues happy for me to do that on your behalf?

[77] **Russell George:** Yes, I would be happy with that, Chair. What is the process over the summer recess? If we are writing to Ministers and third parties now, when we get replies, do we automatically send those to keep the petitioners updated? I can see the clerk nodding.

[78] **Ms Stocks:** Yes.

[79] **William Powell:** That is the way that we operate, is it not? Otherwise, it would be an intolerably long time. There is a huge amount of work going on behind the scenes to keep these things ticking over.

[80] **Bethan Jenkins:** The other issue in the letter is that the Minister said that air security is not devolved, so could we ask the UK Government what action it is taking? It was a joint report, was it not?

[81] **William Powell:** Yes, it was.

[82] **Bethan Jenkins:** As a result of the issues that are not devolved.

[83] **William Powell:** Yes, potentially. We have a correspondence chain with Owen Paterson and he is also an MP for the west midlands, so, in this context, I would be very happy to write to him as well on these matters, because then we would have a belt-and-braces approach. Obviously, he and Alun Davies have fairly frequent engagement on other matters, so, perhaps it is something that they could discuss in the margins of one of their other meetings. Are we all agreed?

[84] **Bethan Jenkins:** Yes.

[85] **William Powell:** Excellent. Thanks for that idea as well. We move now to petition P-03-240, Road safety on the A40 in Llanddewi Velfrey. This petition, as you will recall, was submitted by Llanddewi Velfrey Community Council in July 2011 and has the support of 154 signatures. We have had some significant progress here, and, relatively recently, Joyce

undertook a visit and had a site meeting with representatives of the community council on this matter. That was discussed when we last considered this back in June, at which point I wrote to the Minister for transport, Mrs Edwina Hart. We have a fairly comprehensive response in our public papers, but there is one point that is not addressed, which is the additional information that the petitioner is seeking regarding the Llanddewi Penblewyn improvement scheme and a time frame for that. So, if I write back to Mrs Edwina Hart thanking her for the clarification on the other matters, but asking for that point to be addressed, I think that that would take things a step further forward. Are colleagues happy with that?

[86] **Bethan Jenkins:** I think that it is since 2009 that we have had this; not 2011. I remember it being years ago.

[87] **William Powell:** Yes, I thought that it was—. That is right.

[88] **Bethan Jenkins:** So, I hope that we can finalise this now.

[89] **William Powell:** Yes. We are in a situation where it has been incremental, has it not, as these things often are? However, thanks for that correction; there was a typo here in my papers. Thanks for that. Excellent; good.

[90] The next petition is, again, a traffic-related petition—P-04-319, the Newtown traffic petition. This was submitted by Paul Pavia in—I think that this is correct—June 2011, soon after two of us had arrived in this place. It collected 10 signatures, but an associated petition, which Russell might like to make a brief reference to in a moment, collected approximately 5,000 signatures. It calls upon the National Assembly for Wales

[91] ‘to urge the Welsh Government to: Install a roundabout at the Kerry road junction’

[92] and also to

[93] ‘issue an early start date for construction of a Newtown Bypass’.

[94] I should declare a general interest in this matter, having been part of some ongoing meetings with the senior official, Andy Falley, and other members of the local community, including some of the local councillors forum, including cabinet members, in Newtown. I know that the constituency Member for Montgomeryshire has also been in attendance at those meetings, so I should probably put that on the record. Russell, do you wish to speak?

[95] **Russell George:** I will just declare an interest myself, having been heavily involved in this petition. The petitioner is somebody who works in my office, so I will just put that on the record, as I have in the past. I think that the new Minister has taken this issue on very seriously. I was very pleased that, in a statement last week, she specifically mentioned resolving pinch points in Newtown, so I think that all those who are involved in this petition should be pleased that the Minister seems to be taking this seriously. In her letter she talks about a review meeting of stakeholders taking place shortly; in fact, I think that it is today, as it happens. All we can do is wait for the findings of that review. Perhaps we could write to the petitioner, at least formally, letting the petitioner know about the Minister’s statement last week. I think that that would be helpful to pass on to other people who have shown an interest.

[96] **William Powell:** Absolutely. This is clearly a matter of concern, and needs to be fed back locally. In a situation like this, it must often seem like progress is painfully slow, even though it is taking the course that it has to take. We cannot undertake anything at the moment, ahead of the options review reporting, so it is a question of watching this space, really. I would certainly agree that, with the advent of the new Minister, we seem to have significant

fresh impetus in this scheme, and in one or two other schemes in the Mid and West Wales region that I am aware of.

[97] **Joyce Watson:** First of all, I welcome the fact that we are going to go to an options review. It has to be good news. We all know that there are many opinions on how to resolve Newtown's traffic problems, and many of them are opposing views. That is one thing that is clear. What I hope will happen with this options review is that we will get some clarity and agreement and actually be able to move this forward. That is what I hope. That is what Newtown deserves. It is not just Newtown, of course. Travelling through mid Wales, as I do, quite frequently, I know that it is an arterial road, and that what happens in Newtown affects what happens all the way along that route.

[98] **William Powell:** Excellent. I fully agree with that and look forward to coming back to consider this when we have some solid outcomes from the review that we have been discussing. I see that we are happy to proceed on that basis.

9.45 a.m.

[99] The next item is P-04-393, Llanymynech and Pant Bypass Action Group. This was submitted by Duncan Borthwick in May 2012 and collected 84 signatures. This is one, realistically, where the group is an action group, and, unfortunately, from its perspective, there must seem to be a limited amount of action here, because of issues on both sides of the border. We have commissioned a research brief on this whole area of cross-border working, and that has not been forthcoming as yet, but I would look for it to be available to us early in the autumn term, to inform our work in this and in other petitions. So, we will need to revisit this petition in the light of that wider research brief.

[100] **Russell George:** I support that, Chair. We should discuss this again, once we have that research brief. I am just a bit concerned that the Minister has, potentially, not addressed our letter to her. The reply from the Minister talks about the scheme no longer being a priority and so forth. However, from memory, our letter was asking what the Minister could do with regard to the Llanymynech and Pant area, and that did not necessarily have to be a bypass. I do not have a copy of the letter that we sent, but may I just ask that—

[101] **William Powell:** We can certainly make that available to committee.

[102] **Russell George:** Perhaps I can ask you to revisit the letter that we sent, and if there are areas on which you think the Minister—I am happy to leave it to your discretion, Chair—has not fully replied, you could write back, asking for some more clarification. It was not just about the bypass; it was about smaller improvements, I think.

[103] **William Powell:** Yes—smaller, incremental improvements. It does not appear that the wider bypass will be happening any time soon.

[104] **Russell George:** That is acknowledged and stated in the letter, but I think that, potentially—

[105] **William Powell:** I am happy to have another look at that and at the next tier down for works that might—

[106] **Russell George:** Yes, because I am clear that there has to be a cross-border issue. I am clear that there has to be agreement from those on the English highways side, which has not happened, and they have stated that it is not going to happen. So, we can almost draw a line under that, but let us see what we can do on the Welsh side, other than it being a bypass.

[107] **William Powell:** I recall having written previously—there has been quite a lot of traffic in the transport brief in the Westminster Government. I think that this sits with Patrick McLoughlin, though it was not him that I wrote to; I think that it was one of his predecessors. There has been quite a bit of movement there, has there not? Nevertheless, it is pretty much a matter of public record that there is not going to be a prioritised bypass scheme with support from the UK Government, so we need to look at smaller improvements that may make life easier for the locals.

[108] **Joyce Watson:** That might be the case, but we are the Petitions Committee, and we are charged with doing what the petitioners ask us to do. They are clearly asking us to

[109] ‘call upon the Welsh Government to reinstate plans for the bypass of the villages of Pant and Llanymynech which straddle the English/Welsh border.’

[110] If it is the case that the petitioners want to come back to ask us to do something else, then, you know, we can look at something else, but I really do not know—and I will take advice—whether it is our job to look at anything wider than what the petitions ask for. I do not say this just because it is this petition, but because I wonder how we are going to manage what we do. Are we able to decide as a committee that we should look at something else, other than what we have been requested to look at? That raises so many questions. That is the only reason that I am bringing it to the table, because it seems to me, from what I am hearing this morning, that we are bringing other things into our realms. While they might be important, and we might be able to look at them, they are not actually asked for in the petition, and that is my reason for saying what I have just said.

[111] **William Powell:** I appreciate that call for consistency, which is important. I know that it was a theme when we were looking at the recent petition on recruitment.

[112] **Joyce Watson:** Indeed it was, and we have to be consistent.

[113] **William Powell:** Yes, okay. In any event, we have commissioned a piece of research work that is not available just yet, but it relates to the petition as it stands, and I think that that can certainly inform our action. I am happy to have a look at the particular form of words used in the correspondence to the Minister, to see how I have captured that previously. I am happy to do that.

[114] **Joyce Watson:** That is fine.

[115] **William Powell:** However, your point is well made. Excellent.

[116] We move now to P-04-365, Protect buildings of note on the Mid Wales Hospital site. This was submitted by Mr John Tushingham in February 2012, with the support of 206 signatures. We are familiar with the aims of this petition. I should declare an interest in this matter, in that it is very much in my backyard, in Talgarth. The site is of regional significance, but it happens to be where it is. Also, some of the petitioners are known to me. We last considered this in our committee in March and we wrote, at that stage, to the Brecon Beacons National Park Authority, which is currently at an advanced stage in the development of its local development plan. In fact, we have had notification from the national park that this matter was to be considered at its meeting on 12 July, and it has been recommended by the buildings conservation team within the national park that this site should remain on the local list. Colleagues will also recall that this particular site is also part of an extended conservation area in Talgarth.

[117] On the most recent occasion when we looked at this, there was an indication that this might be a potential first stop on our journey to north-west Wales. If colleagues are happy to

confirm that now, it might be a useful visit, if you are agreeable to that approach. We are making arrangements for collective transport and it could potentially tie in with an initial stop for a comfort break and brief refreshment as well.

[118] **Joyce Watson:** That is fine by me.

[119] **William Powell:** Are other colleagues happy with that? I see that you are. Excellent.

[120] **Bethan Jenkins:** Will the local list be protection enough, or will it still be outstanding with regard to the national listing? It states that the park will be considering the local listing on 12 July.

[121] **William Powell:** The level of protection afforded by that is something that we need to be clear on. I know that you have had experience with the Custom House and other buildings.

[122] **Bethan Jenkins:** Well, it was not listed. However, if it is locally listed, the protection is not as strong as a national listing.

[123] **William Powell:** That does not sit very strongly in the hierarchy of protections, does it?

[124] **Ms Stocks:** Obviously, that is an issue that goes back to the committee's consideration of the Vulcan, where the committee made two recommendations, one of which was on the protection of local listing. The committee wrote to the Communities, Equality and Local Government Committee a few weeks ago, highlighting these issues in advance of its consideration of the heritage protection Bill. In that letter, the committee highlighted this issue about local listing.

[125] **William Powell:** Yes, and where that sits.

[126] **Ms Stocks:** Yes.

[127] **Bethan Jenkins:** Okay; that is fine.

[128] **Ms Stocks:** We are waiting for that response to come back, but that has been raised.

[129] **William Powell:** That is still outstanding, is it not? Excellent.

[130] We will move on to discuss petition P-04-422, Fracking. This is increasingly on our agenda, and more widely in the Assembly. It was a subject of discussion at the cross-party group on energy just last week, when Ed Davey and Alun Davies were among the panel members. This petition was submitted by Friends of the Earth in October 2012, with 914 signatures. We last considered it back in June, and we wrote to Lord Dafydd Elis-Thomas as Chair of the Environment and Sustainability Committee and also to the Minister. We have had a response from the Minister and from the petitioner.

[131] One of the issues of concern to the petitioners is the level of expertise available within the Natural Resources Wales team to evaluate these potential fracking applications. I would be interested to know the level of resource that there is in this particular field, because I know that authorities, for example, within the European Union, have suggested that it could take between five and seven years for the safety of hydraulic fracture as a means of capturing energy to be established. There does seem to be, in some quarters, more of a headlong rush on this one. At the moment, it would be useful for us to have a steer as to the level of expertise among the personnel. Would colleagues be happy for me to write in those terms to seek that

information?

[132] **Joyce Watson:** Yes, but also asking about the level of expertise available to them, because they are not necessarily the same thing. We all build expertise in, do we not? Sometimes you have it in-house, and sometimes you have to bring it in. So, let us just do both.

[133] **William Powell:** Yes, sometimes you buy it in as consultancy. Okay, we need to capture it in that particular way. Would it also be useful for me to write formally to the Chair of the Environment and Sustainability Committee to seek an update for the whole committee with regard to the progress in that committee's work? I am conscious that three of the four of us on this committee now sit on that committee. However, from a formal perspective, it would be useful to get an update on the recent work on unconventional gas because it is a strong issue across Wales.

[134] **Bethan Jenkins:** I do not know if all AMs are on the e-mail system for the Welsh Affairs Select Committee, but it is going to conduct an investigation into shale gas. I am sure that Friends of the Earth Cymru are aware of this, but I wonder whether we can tap into that as a committee. If we decide to take more evidence from people, we could always put in a short submission based on the evidence that we have received, depending on the timelines of that particular investigation, or simply refer the petitioners to it. It depends on how proactive we want to be as a committee.

[135] **William Powell:** If I write to David T.C. Davies, Chair of the Welsh Affairs Select Committee, on that issue as well, we could establish that. That could be useful in bringing a more joined-up approach.

[136] The next update is on P-04-461, Save Ponty Paddling Pool. This petition was submitted by Karen Roberts in March 2013 and had collected 1,212 signatures. We last considered this in May. There were initial queries regarding admissibility and related matters, and that was all sorted at first consideration. We wrote to the Minister and the petitioner, and we have responses from both in our public papers today. I should re-declare my relationship with the petitioner, in that she is a member of the Welsh Liberal Democrat group office. For the sake of consistency, I should declare that matter now. Having said that, it appears that we may well have run the course with this petition, in the light of the fact that it has been considered for listing on three separate occasions, and has not met the criteria.

[137] **Bethan Jenkins:** I know other people who were involved in this campaign, and I also think that we should be referring this petition to the Communities, Equality and Local Government Committee with regard to the heritage Bill. There are issues over when things are listed and what defines appropriate listing. This has been in the community for years, and it is something—

[138] **William Powell:** It is precious to people and there are well over 1,000 signatures here.

[139] **Bethan Jenkins:** The wording of the petition does not allow us to dig deeper, but with regard to access to sport, the point is well made with regard to the fact that you would have to pay for access in the future. This does not allow access for people who perhaps cannot afford it. So, there are other issues there that I am sure that the petitioners and other people in the community would raise in a different way with us or with Ministers in the future.

[140] **William Powell:** That was a very valid point. I have already been in correspondence on that issue to try to flag up a range of heritage issues. I think that the Ponty petition was included in that. If it was not, it certainly could well be one that we could build into it in a

follow-up letter.

[141] Good morning, Dr Blewett-Silcock; we will be with you shortly.

[142] Continuing our consideration of updates to the last few petitions on our agenda today, we have P-04-480, Address Private Sector Student Housing Standards. This petition was submitted by a representative group of Aberystwyth Students Union in May of this year, and has collected 188 signatures.

10.00 a.m.

[143] It is associated with a significant piece of work that the students union has been involved in, gathering data regarding student experience of housing issues, and particular housing difficulties in the private sector locally. We first considered it back in May, and we wrote to the Minister for Housing and Regeneration. The response that we have received, together with further information from the petitioner, is included in today's public papers. My sense is that this is an issue that we have to take further, and that we need to extend our net in terms of taking on the views of quite a number of stakeholders. A number come to mind already, such as the Accreditation Network UK, the Association of Letting and Management Agents, and, indeed, the Association of Residential Letting Agents. We have a significant number of others that have been suggested to us, and they are listed before us. Are colleagues happy with that, and are there any additions that colleagues would like to make to the draft list that has been circulated?

[144] **Russell George:** This is an extensive list, Chair. I am happy with your suggestion to move forward with that, and to write to these organisations over the recess period.

[145] **Bethan Jenkins:** What is the process? Are we writing to them to conduct a small inquiry ourselves, or are we writing to them just to get their views?

[146] **William Powell:** We are seeking their views on the executive summary of the report that the students have come up with, in terms of their experiences. I think that we need to consider—

[147] **Bethan Jenkins:** I think that it would be good for them to give evidence. These issues were live when I was student president at Aberystwyth, and that was some time ago now. Therefore, I think that these issues have to be nipped in the bud. I appreciate that the Minister is doing quite a lot on it, but I think that it would be good to have evidence from them.

[148] **William Powell:** I would be very happy as well to write to the Minister for Housing and Regeneration in the meantime, in parallel to the issuing of this consultation, highlighting the concerns that the petitioners have brought in their latest correspondence, which we have in our papers.

[149] **Joyce Watson:** I think that we should definitely move this forward, because there is a lot of read across. This is about students, but it affects everyone, and we are trying to do something about it here in the Assembly, as is the Government, in particular. I would be up for an evidence session, most definitely.

[150] **William Powell:** Yes, I think that an evidence session could be really quite rewarding, to get that direct, first-hand experience.

[151] **Joyce Watson:** I would agree.

[152] **William Powell:** Good—let us do that. We now turn to P-04-436, Government Expenditure and Revenue Wales. This petition was submitted by Stuart Evans in January 2013, with the support of 27 signatures. It calls on,

[153] ‘the National Assembly for Wales to urge the Welsh Government to put together a Government Expenditure and Revenue Wales report.’

[154] We last considered this in March, and we wrote to the petitioner. Indeed, we have had a considered response from him, which is in our public papers today. I would propose, in the light of the concerns that he is expressing, that we write to the Minister for Finance, highlighting the issues, and asking whether such revenue information will indeed be released by the Welsh Government. Are Members content with that approach? I see that you are—excellent.

[155] Finally, we turn to petition P-04-478 and, indeed, linked to that is petition P-04-482. We have had common correspondence from Sovereign Wales, the petitioner in both cases. There is clearly a link between the two, and we have had shared correspondence from the petitioner on both. Therefore, I think that we could group the next two items, just before going to our evidence session. I think that that would make sense.

[156] **Joyce Watson:** No, I do not think that you can link these two.

[157] **William Powell:** Okay, if that is your wish, Joyce, then we can give them separate consideration. I was just conscious of the passage of time. Anyway, we will start with P-04-478, A simple info pack for all the people of Wales explaining how they can stand as candidates. This petition was submitted by Sovereign Wales, whose petitioning activities we were discussing earlier in the meeting, in May 2013, and had the support of 11 signatures. It calls on,

[158] ‘the National Assembly for Wales to urge the Welsh Government to send out a clear understandable leaflet to all people of voting age in Wales, explaining how they can stand in local, national or Britain wide elections if they so wish.’

[159] Interestingly, there is that link again on accessibility and clarity of information.

[160] **Russell George:** I think, Chair, that we should write at least to the Electoral Commission to seek its advice, and maybe other organisations as well. They are the people that we should be seeking their advice on this.

[161] **William Powell:** Yes, and the Electoral Commission clearly—

[162] **Bethan Jenkins:** What about the Electoral Reform Society?

[163] **William Powell:** The Electoral Reform Society and the Electoral Commission in Wales. I would also suggest the Welsh Local Government Association and One Voice Wales, as the representative body of local councils.

[164] **Joyce Watson:** It is not the only representative body, is it?

[165] **William Powell:** No; there is also the National Association of Councillors, which I am aware of. We will dig out the contact for the—

[166] **Bethan Jenkins:** What about the Commission?

[167] **William Powell:** Do you mean the Assembly Commission?

[168] **Bethan Jenkins:** Yes.

[169] **William Powell:** I think that, potentially, that would be a sensible—

[170] **Bethan Jenkins:** I was just wondering who represents Assembly Members when we talk about these issues.

[171] **Russell George:** Could I just resolve that we write to the people that we have mentioned now, seeking their views?

[172] **William Powell:** Yes. We will seek clarity on the appropriate person. Having clarity in terms of entitlement to stand is clearly a matter of great concern and can lead to all sorts of agonies and difficulties, as we will all recall from earlier in this Assembly. I will be happy to do that. Potentially, we could be looking at undertaking a piece of work on this, but I think that we probably need to see the kind of feedback that we get.

[173] Finally, we come to petition P-04-482, Public noticeboards across Wales notifying the public of who all their political representatives are. This petition was also submitted by Sovereign Wales, also in May 2013, and also with 11 signatures. Again, there are a lot of common themes here. I think that we should write to the bodies that we identified earlier. I think that probably a similar list would make sense.

[174] **Russell George:** Why do we not write to all of the people that we just mentioned in relation to the previous petition?

[175] **William Powell:** Indeed. Exactly.

[176] **Russell George:** We could ask the same kind of question.

[177] **Bethan Jenkins:** The only thing that I was thinking of in terms of the previous petition is that political parties have information on how to stand as a candidate. I am not sure whether that is public. If you have to seek out a political party, we could ask political parties on a general basis what they generally do, because you cannot exclude political parties from this.

[178] **William Powell:** No. We could write to the chiefs of staff of all principal parties that are registered in Wales and have recently been standing in these elections. I think that that would make a lot of sense.

[179] **Russell George:** I would be very surprised if the information that the petitioners want is not available on the web somewhere. I suppose that what they are querying is how easy it is to find. I would be very surprised if it was not available.

[180] **William Powell:** Clearly, the aspiration in this final petition is to have a traditional means of making that available on noticeboards. Obviously, they could be given a level of representation that people have, and different tiers, which could be quite an extensive noticeboard. We need to think of the implications of that. Nevertheless, the point is well made and we can dutifully take that forward by writing to stakeholders. Good. Excellent.

10.08 a.m.

P-04-452 Hawliau Cyfartal i Bobl Ifanc Tiwb-borthedig—Sesiwn Dystiolaeth
P-04-452 Equal Rights for Tube-fed Youngsters—Evidence Session

[181] **William Powell:** It is a great pleasure to welcome Dr Tymandra Blewett-Silcock as lead petitioner. I would also like to thank you very much for providing your paper, which will inform this session today. Perhaps I could ask you to make an initial statement, just to check the levels and so on. We will then move to questions.

[182] **Dr Blewett-Silcock:** First of all, thank you very much for having me. I will try my best to remember everything that I wanted to say. It is a very long way down there to the other end of the table.

[183] **William Powell:** Looking at the particular issues that have been flagged up by the case of Poppy Blewett-Silcock, could you please explain the health and social care needs that apply and the extent to which those were not being met?

[184] **Dr Blewett-Silcock:** If I can use my paper—

[185] **William Powell:** As a point of reference, that is absolutely fine.

[186] **Dr Blewett-Silcock:** What I have started with is the continuing healthcare label or definition process. The problem that we and many other families have—it is not just our family in the Caerphilly borough—is that even a blind, wheelchair-bound, tube-fed, degenerative and terminal condition child, and epileptic children on quite strong medication, do not qualify for continuing healthcare, which is questionable in itself, because being tube fed is not a natural state. It needs nursing and all sorts of care that are not a normal condition to be in, so being able to look at continuing healthcare processes would be interesting for the future and might solve things at a much earlier level, than going through all the other fights that we and many other families have had to go through.

[187] We are in a personal situation, as are many other families, in that you can sit in a meeting like this, only with a much smaller table, where you have the manager of the Aneurin Bevan Local Health Board and the manager of social services, and you desperately need something and have been assessed by a social services occupational therapist as needing that item and they are both saying that they cannot help you. One is citing that this child does not have enough health needs, using that phrase, and the other one is saying that your child has significant health needs. So, you are listening to that and you are thinking ‘Well, are they not listening to each other?’ You are asking them ‘Who will help us? We don’t want to have to ask for this equipment, but we have now been assessed that this is for health reasons, health and safety or a myriad other reasons. We are not the first family to have been through all of this, and we will not be the last, but we need them to look at this in a sensible way and work together. It is as if you cannot get them to work together, because they will not be told by anyone and, therefore, the only possibilities that we have are to come to this level or, even worse, families having to go to the press to get any action and resolution. We had to go to the BBC. No family should have to do that, because, quite apart from the stress that it entails, there is come-back if you dare to speak out like that, and we should not have to go through that process when we have an awful lot going on with our daughter as it is on a daily basis, as do other families. It is a huge care burden. I am rambling on now—

[188] **William Powell:** Not at all; this is really important personal testimony.

[189] **Dr Blewett-Silcock:** So, the only thing that I can think of, and it is probably simplifying the process, is if one cannot help and the other cannot help, there needs to be a third category. It may be very simplistic—a 50:50 funded child, or if they want to go into all

sorts of matrices about a 70:30 or 60:40 child, then so be it. However, there must be a middle ground. They have to accept responsibility, like we have to. We need the help. We cannot not have that equipment—a medical bed, slings and things like that.

[190] Even though people think that our whole problem has been sorted now with direct payments, because we had to go to the press, the next mini battle for us is that we need new slings. I do not want to go to social services and ask for them, because I know that it will probably take a year of exactly the same wrangling that we have been going through for two years to try to get direct payments, which were available anywhere else in Wales and the UK. We all understand the financial issues, however, we are also under a huge financial burden. If we could go out and buy that medical bed and slings for ourselves and not involve anybody and not have to beg for help, then we would. We cannot, because we are often a wage down. There are all those issues going on. I am just asking for your help.

10.15 a.m.

[191] If you need advice or any insider knowledge about what it is like to be a parent-carer, then I know a lot of parents that would gladly feed in their stories and their personal problems to try to get some solution. This is not for us; it is for everybody else that is just too tired to sit here and try to get people to see sense. I do not think that it is a complex situation. If there are children that are in that middle ground, then there must be some kind of solution to any respite and equipment problems. I will stop talking now.

[192] **William Powell:** Thank you very much. The way that you have taken on the role of being an advocate for so many other families, rooted in your own experience, is moving. It could well be that when we consider after the session the way that we can take this forward, you could be of assistance to us in providing further contacts so that we could extend the piece of work to another level.

[193] Is there a particular way in which you feel that things broke down in your own case, in terms of how Poppy's case was looked at? Is there any aspect that you feel particularly needs to be urgently addressed in the way in which such cases are assessed in the future?

[194] **Dr Blewett-Silcock:** It is this definition almost of a problem child, for anything in the future, for every family. You get a meeting, you get your notes, and you want to hear someone say, 'It is not one or the other; it is this. Therefore, it is our joint responsibility to provide x within reason.' We do not expect the earth. It is about having that easy solution, but we keep thinking, 'Well, am I asking too much, because it does not seem to be very easy to get these things?' I just think that you need a quick matrix or a label for that child.

[195] **William Powell:** Yes, to have clarity of definition is really important.

[196] **Dr Blewett-Silcock:** And to be able to ask, because the big problem is if you ask, 'Well, who will help us?' or if you ask 'why' about anything, that is perceived as being so wrong. We are not the only family to be in that situation.

[197] **William Powell:** Thank you for that. We will now turn to Bethan, and then to Joyce.

[198] **Bethan Jenkins:** Thanks for giving your evidence; it was really interesting to hear and I am sorry you have had to go through everything that you have had to go through.

[199] I was just wondering whether it is less about a new category and more about health and social care potentially being joined up, so that your child would have a care pathway, as with other health definitions, so that that would follow through? For me, it should not have to be for a parent to sit in a room and watch those two separate departments fight or claim that

they cannot afford it. It should be for them, before you enter the room, to already have an integrated budget, so that you do not have to define your child in a different way. It is just turning the debate around, because I really do not see why your child should have to be defined in a different way. She should be treated fairly regardless of the illness and appreciating the seriousness of it. I think that there is backroom work that those two departments have to do.

[200] There are movements for health and social care to work more closely. For example, in my area, Abertawe Bro Morgannwg health board has seconded staff to work within the council's social services team on care of the elderly, because it is closing a hospital for older people in the area. Is that something that you have thought about, or is the defined category something that you have come up with as a charity because it is something that all the parents are agreed upon? Sorry for the convoluted question.

[201] **Dr Blewett-Silcock:** It is just that the label to me seems a simplistic solution for the ideal situation that you are describing. At the moment, for example, Poppy is 10, and we have spent 10 years in the same position and nothing is changing and nothing is moving to get there. That would be ideal, but—

[202] **Bethan Jenkins:** You are looking at the short term at what you could potentially do, and if you had a defined category, where would that list end? Some people may fall out of the loop. I think that if you centre on an individual care pathway for a child, then that should cover all the individual needs, as opposed to a defined category, which could make them fall out of the system again. That is something that our committee can look at further.

[203] **Joyce Watson:** Good morning. Thanks for being here and for bringing this to our attention, because, otherwise, it is something that we might not have focused on and I am pleased that we are doing that. I am with Bethan in terms of labels and categories, because it is never a catch-all situation. That is why you are here, because you have fallen outside of something at the moment. I am not an expert and I am willing to take anybody's views on board. What I find rather disconcerting in all of this, in the situation that you find yourself in, is the fact that this particular council seems to be among a minority, according to what you are saying, in terms of local authorities that will not allow the use of direct payments. I think that there is something to be done there in terms of a framework for local authorities to work together so that people who move around get exactly the same treatment wherever it is in Wales that they, or their children, happen to reside. That is completely unacceptable behaviour in my view. So, if there is anything that we can do to tackle that one aspect straight away, then I think that we ought to do that.

[204] Also, why is it that these partners are trying to resist helping you and why is it that you cannot access any advocacy? Individuals in your situation need advocacy, because not everybody is going to be able to fight their corner. You have been able to fight your corner and it is a fight that I am sure you could have lived without. You have kept going, but there are people who are not going to be empowered, who are going to give up immediately, or not even know where to start. So, advocacy is another area that we could look at. If you could help with those two things first, I would be grateful.

[205] **Dr Blewett-Silcock:** On advocacy, because she is non-verbal and cannot use a communication device, she falls through that loophole of not being able to get an advocate. If she was able to work with a worker and express her views, then we could have an advocate. However, because she is non-verbal and cannot make her views known, because it is our battle for her, we cannot get an advocate from anybody. I have contacted all the new advocacy groups. There are a lot of different advocacy groups now, which have been trying to address this issue over the last few years, but there is that gap for this kind of child.

[206] I have spoken to Carers UK and Carers Wales and they just cannot provide the advocacy possibility, hence my request that Cath Lewis would sit in on meetings. She has been doing that for quite a while now. She is an ex-social worker and I think that she is finding it quite interesting to see how we are treated. The rest of the people at the meetings do not necessarily know her background and what she does now. She is just there as a personal friend, if you like. She is an extra pair of ears, so that next time when you go to a meeting in six months or 12 months and they say, 'No, that is not what we agreed', then she can say, 'Well no, hang on a minute, that is what you agreed and you said you would do'. She is party to that and that is worth a lot. You start to think that you are going a little bit mad, and you think maybe that is the idea. You are almost so tired that they are trying to make you believe that that is not what was agreed at the last meeting. So, it is lovely to have that back-up and that support. Sorry, I cannot remember what your other question was.

[207] **Joyce Watson:** The other question was about the difference between Caerphilly council's approach and that of other authorities in helping with direct payments. If they are in the minority as one of very few who are not allowing that to happen, which would help, should we move to a situation where there is a framework that all local authorities work towards? If you moved, you would probably be in a better position, but if somebody moved another way, they would perhaps find that what they had was not available to them, and that is not right.

[208] **Dr Blewett-Silcock:** Going to the press and the BBC in particular meant that I got my meeting with social services and health at the very highest level, which is what I had been trying to get for probably more than two years. They have agreed to start our direct payments as a test case. I think that it was only three boroughs in Wales that I could not confirm whether they would not give direct payments for a tube-feed-trained personal assistant. Given the charity work that I do for Parents of Partially Sighted and Blind Youngsters, I am able to speak to families who are in receipt of them, so it is not just notional, assuming that it is done in the next borough; I know for sure because parents are telling me what hours they are getting, what kind of personal assistant training there is and what people they are getting to do that. I do not know why there is resistance. I can only put it down to—and saying this will be very controversial—the fact that they have never done it before and are reticent to do that. It would not mean a whole new set of things to learn. Maybe they did not want to do that for as long as they could get away with not doing it. I do not know.

[209] However, there are many families that would want to go down that route now, and I have been contacted by a few families, which is great. Having seen the press interest, they are coming to me and asking what I had to do and how to go about it. Hopefully, that will get them in the learning curve that they should have been in whenever the direct payments started, which was about 2000, I believe. It is very frustrating to battle against that resistance when you are told what direct payments are for and the flexibility that they offer and read that on national websites. You are reading all of this and yet you are encountering the polar opposite of that willingness to help and the freedom to get the help that you need. In our case, particularly, when Poppy was ill, I could not get respite, because I could not take her to that respite centre, but now, fingers crossed, I think we might be able to get direct payments set up by December, so if and when she is ill, which she hopefully will not be, I will be able to have a break when I have not slept all night. That is the key thing for us as a family and many others I am sure. That is where we will use that possibility the most.

[210] **Joyce Watson:** Going back to my question, do you think that it would help if we had a framework that captured best practice so that that best practice would become the practice? Again, coming back around, you cannot get advocacy in your case, which might be the case for the others, and you cannot be guaranteed an outcome. We are here as Government, so what can we do to assist? Do you think that a framework might be a good idea?

[211] **Dr Blewett-Silcock:** I am sure that it would, but all the other boroughs seem to be doing it fine so what is different? Is it a mindset or is it the fact that they already have that in place? I do not know, but anything that would help that process, such as advising people to do it in a set way, would be great. Only a minority of boroughs that seem unable to do that, so the answer is 'yes'; if there was absolute set guidance on that, then they would have to do that, would they not?

[212] **Joyce Watson:** Finally, can you let us know, if you have not done so already, the number of local authorities that are not allowing access to direct payments?

10.30 a.m.

[213] **Dr Blewett-Silcock:** There were three in which I could not speak to an independent living adviser or group manager to absolutely, definitely confirm. I did not want to say that there were three—

[214] **Joyce Watson:** But, now you have.

[215] **Dr Blewett-Silcock:** Yes. Caerphilly is involved in the other two adjoining boroughs. Now, if we are setting a test case, perhaps it will be zero in 2014.

[216] **William Powell:** Russell George has indicated that he has a question, and then we will finally move to Bethan.

[217] **Russell George:** Thank you for coming to us today, for your time and for being so open with us. I appreciate that. With regard to the continuing care guidance, what, do you think, needs to be changed in that? Does that need to be changed? What are your thoughts on that?

[218] **Dr Blewett-Silcock:** I think that having to sit at a panel—and we have been through three and failed all three times. Again, does a parent need to be there? I found that, as a parent, you want to focus on the positives, but, in that process, you have to almost list every negative there is, and any potential illness or problem with your child. I do not want to do that. I would rather not. Many parents, because they do not want to do that, will play their child's condition down. Being tube-fed, and, quite apart from anything else, if a child is epileptic and needs medication—and if he or she can seize so badly that they end up in an accident and emergency department—or a child with a terminal condition, I cannot see why that does not result in a CHC label. It totally mystifies me. Then I heard recently that an autistic child with no what I would call health needs got a CHC. I do not know what it is called; the definition.

[219] **Russell George:** It is Asperger's syndrome, is it not?

[220] **Dr Blewett-Silcock:** Yes. With that system, in itself, I understand that you are talking about that middle aspect. There are all sorts of different conditions, but, basically, they are all the same. We have been told that Poppy does not have—I cannot remember the exact phrase—any major health issues. All of them have aspiration problems. If they swallow, it goes into their lungs. All of this happens because of the tube-feeding and the lack of tone, and the terminal thing. How is that not described as significant, as well as the continuing healthcare that she will need, and because of the degenerative side of things, it will only get worse. I do not see how a CHC label cannot encompass all of that middle-ground child. It is kind of that at the background of everything. You can understand why the health service does not have the money to cover every single child. However, on the other hand, there are many different aspects to a lot of severely disabled children that perhaps should result in that CHC definition.

[221] **William Powell:** Daw'r cwestiwn **William Powell:** The final question comes
olaf oddi wrth Bethan Jenkins. from Bethan Jenkins.

[222] **Bethan Jenkins:** I will just come back to another question that I had earlier with regard to advocacy. I noticed that you said that, because your daughter cannot communicate, she does not qualify. I was just wondering whether you have had a discussion with the children's commissioner with regard to that, because, obviously, enshrined in our law is the rights of the child. If you are not allowed—I presume—to have a formal advocate, and your child cannot communicate, we need to really look at this as a special category. I am not a specialist in this area either, but I would like to know what you have done to look at this, so that we can potentially assess, as a committee, any options to recommend for the future.

[223] **Dr Blewett-Silcock:** We have spoken to the children's commissioner over the last few years and he was actually quoted, during the BBC interest, that it was the human rights of the child being totally ignored, because she should not be involved in that wrangle of the joint care or joint funding. So, we have spoken. I have had advice for them as to which groups to approach to try to get advocacy—each one that I have spoken to will give me another number and name. I have gone around every single person, so there is no-one I have missed in Wales to be able to provide the advocacy that we needed, hence me contacting Cath and jokingly saying that I was going to give everybody her name, even though it is not her job. This demonstrates that there is such a need. I am almost interested in doing it myself, but it is about having the time, really.

[224] **Bethan Jenkins:** Just to indulge, it is obviously something that you would want to be set in stone. As you said, you get that support to say that the minutes were true, but what we need to see is that it is agreed and formalised by any form of advocate, because you are in a position of insecurity, not knowing whether your voice is being doubted constantly just for wanting to have services for your daughter. So, these are all things that we need to look at. Thank you for coming today.

[225] **Dr Blewett-Silcock:** If there was something official, then that would be great.

[226] **William Powell:** Dr Blewett-Silcock, I would like to thank you, on behalf of the committee, very much indeed for the time that you have taken to be with us this morning, for the papers that you have presented and, indeed, your commitment to help to continue to support us in our further consideration of your petition to try to bring about some of the improvements that clearly need to happen. We are going to take time to consider this session. We would like you to have the opportunity to take your space in the gallery and we will give you the courtesy of taking your place before we start our consideration. Thank you very much indeed for being with us today.

10.37 a.m.

**P-04-452 Hawliau Cyfartal i Bobl Ifanc Tiwb-borthedig—Trafod y Sesiwn
Dystiolaeth**

P-04-452 Equal Rights for Tube-fed Youngsters—Discussion of Evidence Session

[227] **William Powell:** That was a very powerful session. I was struck, in some ways, by some of the similar themes that arose today and in the previous evidence session in terms of issues around equality of access and bureaucracy, and the fact that it must seem so difficult to navigate your way through as a carer when you encounter such obstacles.

[228] Colleagues, I sense that there is an appetite to take this forward.

[229] **Bethan Jenkins:** We should wait for the witness to get to the public gallery. We could sing a little song in the interim. [*Laughter.*] Like being put on hold.

[230] **William Powell:** Okay. The lead petitioner is now present in the public gallery. Colleagues, what do you feel is the best way forward? I am certain that there is an appetite for us to take this matter forward in a number of different ways. As Dr Blewett-Silcock said, she is prepared to assist us in advising us on other potential stakeholders and other families who would be prepared to contribute to our work in assessing this on maybe more of an all-Wales basis. Joyce, you have indicated.

[231] **Joyce Watson:** The first thing we have to do is to look at the UN Convention on the Rights of the Child, because everything we do operates under that, as Bethan quite rightly alluded to early on, and everything that falls out from that, or does not, it seems, in this case. So, if we start with a rights-based approach, we will at least be travelling, in my opinion, in the right direction.

[232] I notice from the correspondence that we had from the Minister that there are no prescriptive—well, I am not saying that there are no prescriptive tools, but guidance is not a prescriptive tool. There is guidance, and it has been issued. I am sort of in two places here, so I would like to take some evidence about whether we ought to move guidance to prescription and, if we did, what the consequences would be of that.

[233] **Bethan Jenkins:** I am sorry, could you repeat that?

[234] **Joyce Watson:** Moving from guidance to prescription; in other words, what we were talking about. If we look at, instead of saying, ‘In these cases, you may or you may not do whatever’, and pinning it down to, ‘In this case, you will’, what I am afraid of is excluding more than we are including. I would want to examine those things with the correct bodies, whoever they might be. One thing that is obvious here is that people have tighter budgets. I am not sure, from what I have heard this morning, that we will not see more of this, and I do not want to see more of this. No-one in this room wants to see more of this. So, there has to be greater clarity for the needs of a child to be cared for and supported financially by social services and health, because there is clearly a gap here and these children are falling though. My worry is that there will be many more—maybe greater numbers—doing that as finances get even tighter. That is what I want to say.

[235] **William Powell:** I think, in a future evidence session, we need to draw on those themes. Who do colleagues feel it would be appropriate to invite in for a future evidence session? We have the possibility of other stakeholders, which the lead petitioner can advise us on, but what about from the Government side?

[236] **Bethan Jenkins:** I think that we need to do some more work first, before we have people in. With guidance, it is just that. Quite often, when we are talking about health issues, it needs to be stronger than guidance, because if local health boards’ chief executives do not have a clear target on it, they will not administer the trickle-down approach. That is true of issues that I work on with regard to muscular dystrophy and eating disorders. Until it becomes statutory—

[237] **William Powell:** Yes, central to the agenda, really.

[238] **Bethan Jenkins:** So, we need to look at that, because, if this group of people is falling outside the guidance, then it needs to be strengthened. So, that is something that I would want us to look into. Also, with regard to social care and healthcare, I would like us to write to the local health boards to see, at the moment, across Wales, what they are doing. As I

mentioned, in my area, it does happen—they are working closer on some issues. Is that a trend across Wales or is it just in my area or is it patchy, especially in Caerphilly, where there are obviously tensions? Can we understand why that is? Also, with regard to the well-being Bill that is going through, we will be reaching the next stage of that soon, so are there ways that we can look to see whether there are amendments that can be put in? I know that this is bureaucratic-speak and that it is not friendly in that sense, but could we look to see whether there are amendments that we could put in on this particular issue?

[239] **William Powell:** That is the way in which business has to be done, is it not?

[240] **Bethan Jenkins:** The other thing is that I forgot to ask the lady about whether she had complained to the ombudsman with regard to this issue, because the ombudsman produces case studies and a case report on everything that he looks at. I would be curious to know, because then we can learn from best practice in the future.

[241] **William Powell:** I am sure that we can capture that. There is an indication that the answer is ‘no’ on that particular point. Also, I think that, in writing to the Minister, I would like to raise whether there will be a review, two to two and a half years in, by the Welsh Government of the way in which direct payments are working, because the guidance was issued to local authorities back in 2011. We are now reaching more or less the half-way point of this Assembly, and I think it would be useful to see how that is working across Wales.

[242] **Russell George:** Has the Health and Social Care Committee done any work on this at all that we know about?

[243] **William Powell:** I do not believe so.

[244] **Russell George:** I wonder whether we should, not ask it to do another piece of work, but at least write to the committee to see whether it has had any correspondence on this that has perhaps not been formally taken forward in committee but may be useful for us to take note of.

[245] **William Powell:** I am happy to write to David Rees, the new Chair, on that issue.

[246] **Ms Stocks:** It might be worth saying that children’s health comes under the Children and Young People Committee’s responsibility in terms of committee work. This committee did write to the Children and Young People Committee, and you may recall that we got a response back from the Chair saying that the committee had capacity issues, but felt it was an important issue. That was one of the reasons why this committee chose to get Tymandra in.

10.45 a.m.

[247] **Russell George:** That is why I did not want to automatically write to that committee and ask whether it can look at this, but just ask them what work or evidence it has received on this in the background, which would help the committee.

[248] **William Powell:** That would help to inform the next stage, would it not?

[249] **Russell George:** Yes.

[250] **Bethan Jenkins:** We have not done anything on it yet.

[251] **William Powell:** We know that.

[252] **Ms Stocks:** The health committee has been considering the social services Bill, so it

may be that the committee will feel that there is a value in that.

[253] **William Powell:** We could also enquire as to whether this has been an agenda item at all in the social services advisory group, which I know is quite an important forum in taking these issues forward.

[254] **Russell George:** I think that we have a bit of information there to look at over the recess. Perhaps we can bring this back quite early when we come back.

[255] **William Powell:** Indeed. We will sift through these different issues.

[256] **Bethan Jenkins:** When I do stuff, I always collect case studies, and we have heard one case, but I know that there are other cases. Obviously, there are data protection issues, so we should not attach names, but perhaps we could collect that. When we talk to the Minister and the committee, it is always stronger if we have examples of personal experiences, I feel. If there are a number of families suffering this, that makes it much stronger than it just being about what we think.

[257] **William Powell:** Absolutely, I agree. I think that we have a whole suite of things that can usefully be done there. We will make sure that we take this forward. Again, I am sure that you would agree with me that it was a moving, but very informative session. Our total respect goes to Dr Blewett-Silcock in terms of what she has brought to this and the role that she is taking on as an advocate for those who do not have the capacity to speak for themselves. So, thank you very much to her.

[258] That concludes the final meeting of what has been a busy term, and, indeed, Assembly year for the committee. I have a couple of issues to flag up today. We have the Stop People Trafficking and Slavery in Wales presentation at 1 p.m. on the Senedd steps. Tomorrow at 1 p.m., we have the robotic assisted laparoscopic prostatectomy petition. Before my final announcement, I would also like to remind Members that we will be out and about, as I referred to earlier, at the Royal Welsh Show, the Eisteddfod and the Usk show over the summer—July, August and September—and there will also be a petitions presence at other Assembly outreach events during the summer.

[259] The final announcement that I have to make is to register my thanks to Naomi for what she has done since returning to the committee, because I received news yesterday that, as part of a review that has been undertaken of the committee service, we have been allocated some additional resource in the form of a new staff member who will join the team from the autumn. As part of that reallocation of roles, Naomi will leave us for new challenges with the Environment and Sustainability Committee, where she will be part of the clerking team as deputy clerk. So, three of the four of us will still have regular contact with you, Naomi, but I am extremely grateful to you for the work that we have had through this past year, bringing on board your earlier experience, when you were originally the committee clerk, prior to the earlier clerking period. We are extremely grateful.

[260] **Bethan Jenkins:** Let us see how long it takes you to come back. [*Laughter.*]

[261] **William Powell:** We are extremely grateful to you for all that you have done. We look forward to the new arrangements that have been put in place for the autumn, but there will be continuity in terms of Siân and Kayleigh being with us. So, thank you very much indeed, and thank you, Members, for your attendance today and I wish you a very happy summer break, but we have two or three pretty busy days ahead. Diolch yn fawr.

*Daeth y cyfarfod i ben am 10.49 a.m.
The meeting ended at 10.49 a.m.*

