### Y Pwyllgor Deisebau Petitions Committee



David Rees AM Chair of the Health and Social Care Committee National Assembly for Wales Bae Caerdydd / Cardiff Bay Caerdydd / Cardiff CF99 1NA

Our ref: P-04-452

23 July 2013

Dear David

The Petitions Committee has received the following petition from Dr Tymandra Blewett-Silcock which collected 142 signatures:

We call on the National Assembly for Wales to urge the Welsh Government to ensure that funding is made available to ensure that the vital equipment and services required by tube-fed children and young people are made available to them.

For example, equal rights for tube-fed youngstersin the Caerphilly County Borough Council currently fall between 2 defined categories of need. The Aneurin Bevan Health Board say as they are not Continuing Health Care (CHC) children - 'only tube-fed' - they cannot fund the vital equipment and services we need. Caerphilly Social Services also say they cannot help as these children 'have significant health needs'. These definitions exclude and therefore discriminate against Tube-fed Youngsters and we demand an investigation into this practice in Caerphilly. Whilst our Youngsters do not 'qualify' for help from either Health or Social Services in the Caerphilly Borough we still have a Youngster with 24/7 care needs - the same as a newborn - often with disabilities due to a life-threatening illness.

#### **Additional Information:**

Our Youngsters need a 'label' in order to be able to automatically access funding for vital equipment and services. At present inter-departmental financial wrangling takes place on request for anything for a Tube-fed Youngster and this should not

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Croesewir gohebiaeth yn y Gymraeg a'r Saesneg/We welcome correspondence in both English and Welsh

involve Parents / Carers. We just need the help for our Youngsters as quickly as possible. We ask that a quick, common-sense, long-term solution be achieved for our Youngsters and for the sake of the health and wellbeing of their Parents / Carers.

We have previously written to the Children and Young People's Committee on this petition, but as the Health and Social Care Committee are scrutinising the Social Services and Well-Being (Wales) Bill, we agreed to make you aware of this petition.

At our recent meeting on 16 July, we took oral evidence from the lead petitioner. A copy of the draft transcript is enclosed.

We would like to highlight the following issues which we heard in the evidence session in advance of your Stage 2 scrutiny of the Bill:

- Difficulties faced by families in qualifying for continuing healthcare. We heard that Tymandra was told by the Health Board that her daughter did not have any significant health needs, whereas the Local Authority told her that her daughter did have significant health needs. We are aware that the Health and Social Care Committee have recommended to the Welsh Government a separate Bill on integrated care;
- That a very small number of local authorities are still not allowing access to direct payments;
- Lack of advocacy support available to those who are non-verbal and unable to use a communication device: and
- The impact that not being able to access support easily has on families.

Yours sincerely

William Powell AC / AM

Cadeirydd / Chair

Enc: Petitions Committee transcript 16 July 2013.



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

Y Pwyllgor Deisebau The Petitions Committee

Dydd Mawrth, 16 Gorffennaf 2013 Tuesday, 16 July 2013

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

- [1] **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.
- [2] **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.
- [3] **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?
- [4] **Dr Blewett-Silcock:** If I can use my paper—
- [5] William Powell: As a point of reference, that is absolutely fine.
- 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.
- 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—

- [8] William Powell: Not at all; this is really important personal testimony.
- [9] **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.
- [10] 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.

- [11] 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.
- [12] **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.
- [13] Is there a particular way in which you feel that things broke down in your own case, in terms of the way in which 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?
- [14] **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.
- [15] **William Powell:** Yes, to have clarity of definition is really important.
- [16] **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.

- [17] **William Powell:** Thank you for that. We will now turn to Bethan, and then to Joyce.
- [18] **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.
- [19] 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.
- [20] 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.
- [21] **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—
- [22] **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.
- [23] **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.
- [24] 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.

- [25] **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.
- 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.
- [27] **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.
- [28] **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.
- [29] 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.

- [30] **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?
- [31] **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?
- [32] **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.

- [33] **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—
- [34] **Joyce Watson:** But, now you have.
- [35] **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.
- [36] **William Powell:** Russell George has indicated that he has a question, and then we will finally move to Bethan.
- [37] **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?
- 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.
- [39] **Russell George:** It is Asperger's syndrome, is it not?
- [40] **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.

- [41] **William Powell:** Daw'r cwestiwn **William Powell:** The final question comes olaf oddi wrth Bethan Jenkins. from Bethan Jenkins.
- [42] **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.
- [43] **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.
- [44] **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.
- [45] **Dr Blewett-Silcock:** If there was something official, then that would be great.
- [46] 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

- [47] **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.
- [48] Colleagues, I sense that there is an appetite to take this forward.
- [49] **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.
- [50] 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.
- [51] **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.
- [52] 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.
- [53] **Bethan Jenkins:** I am sorry, could you repeat that?
- 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.
- [55] **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?
- [56] **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—

- [57] **William Powell:** Yes, central to the agenda, really.
- [58] **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?
- [59] William Powell: That is the way in which business has to be done, is it not?
- [60] **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.
- [61] 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.
- [62] **Russell George:** Has the Health and Social Care Committee done any work on this at all that we know about?
- [63] William Powell: I do not believe so.
- [64] **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.
- [65] **William Powell:** I am happy to write to David Rees, the new Chair, on that issue. I will happily do that.
- [66] **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.

[67] **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.

- [68] William Powell: That would help to inform the next stage, would it not?
- [69] **Russell George:** Yes.
- [70] **Bethan Jenkins:** We have not done anything on it yet.
- [71] **William Powell:** We know that.
- [72] **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.
- [73] **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.
- [74] **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.
- [75] **William Powell:** Indeed. We will sift through these different issues.
- [76] **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.
- [77] **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.
- [78] 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.
- [79] 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.

- [80] **Bethan Jenkins:** Let us see how long it takes you to come back. [*Laughter*.]
- [81] 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.