# Cynulliad Cenedlaethol Cymru
# The National Assembly for Wales

## Y Pwyllgor Plant a Phobl Ifanc
## The Children and Young People Committee

## Dydd Iau, 9 Chwefror 2012
## Thursday, 9 February 2012

**Cynnwys**
**Contents**



Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynddi yn y pwyllgor. Yn ogystal, cynhwysir cyfieithiad Saesneg o gyfraniadau yn y Gymraeg.

These proceedings are reported in the language in which they were spoken in the committee. In addition, an English translation of Welsh speeches is included.

**Aelodau'r pwyllgor yn bresennol**
**Committee members in attendance**

| | |
|---|---|
| Christine Chapman | Llafur (Cadeirydd y Pwyllgor)<br>Labour (Committee Chair) |
| Jocelyn Davies | Plaid Cymru<br>The Party of Wales |
| Keith Davies | Llafur<br>Labour |

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|---|---|
| Suzy Davies | Ceidwadwyr Cymreig<br>Welsh Conservatives |
| Mark Drakeford | Llafur (yn dirprwyo ar ran Jenny Rathbone)<br>Labour (substituting for Jenny Rathbone) |
| Julie Morgan | Llafur<br>Labour |
| Lynne Neagle | Llafur<br>Labour |
| Eluned Parrott | Democratiaid Rhyddfrydol Cymru (yn dirprwyo ar ran Aled Roberts)<br>Welsh Liberal Democrats (substituting for Aled Roberts) |

**Eraill yn bresennol**
**Others in attendance**

| | |
|---|---|
| Pamela Boyd | Cymdeithas y Nyrsys Newyddenedigol<br>Neonatal Nurses Association |
| Helen Kirrane | Rheolwr Ymgyrchoedd a Pholisi, Bliss<br>Campaigns and Policy Manager, Bliss |
| Dr Jim Richardson | Aelod o Fwrdd Coleg Brenhinol y Nyrsys Cymru dros Blant a Phobl Ifanc<br>Royal College of Nursing Welsh Board Member for Children and Young People |
| Lisa Turnbull | Cynghorydd Polisi a Materion Cyhoeddus, Coleg Brenhinol y Nyrsys Cymru<br>Policy and Public Affairs Adviser, Royal College of Nursing Wales |

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

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|---|---|
| Claire Griffiths | Dirprwy Glerc<br>Deputy Clerk |
| Sarah Hatherley | Gwasanaeth Ymchwil<br>Research Service |
| Claire Morris | Clerc<br>Clerk |

*Dechreuodd y cyfarfod am 9.15 a.m.*
*The meeting began at 9.15 a.m.*

## Cyflwyniad, Ymddiheuriadau a Dirprwyon
## Introduction, Apologies and Substitutions

[1] **Christine Chapman:** Good morning, everyone, and welcome to the Children and Young People Committee. I remind Members that mobile phones, BlackBerrys and pagers should be switched off. We operate through the media of Welsh and English, and headsets are available for simultaneous translation. In the event of an emergency, an alarm will sound and ushers will direct everyone to the nearest safe exit and assembly point. We have had apologies from Aled Roberts and Jenny Rathbone; I welcome Eluned Parrott, who is substituting for Aled, and Mark Drakeford, who is substituting for Jenny. Welcome to both of you.

9.16 a.m.

## Ymchwiliad i Ofal Newyddenedigol—Tystiolaeth gan y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
## Inquiry into Neonatal Care—Evidence from the Minister for Health and Social Services

[2] **Christine Chapman:** Our first substantive item is the inquiry into neonatal care. The committee agreed to hold this mini inquiry as a follow-up to the previous Health, Wellbeing and Local Government Committee's report into neonatal care in Wales in July 2010. We have had an update from the Minister for Health and Social Services, which shows the current position regarding the 18 recommendations contained in that report. Members will have seen the update, which has been circulated with the papers for today's meeting. We have a number of organisations with us today, and they have all provided evidence to this inquiry. I would like to put on record our thanks to the Minister for providing an update paper.

## Ymchwiliad i Ofal Newyddenedigol—Sesiwn Dystiolaeth 1
## Inquiry into Neonatal Care—Evidence session 1

[3] **Christine Chapman:** I welcome to the meeting our first witness, Helen Kirrane, who is the campaigns and policy manager for Bliss. Thank you for attending today, Helen; we appreciate it. Thank you also for providing a paper in advance. Would you like to say a few words to start, or go straight into questions?

[4] **Ms Kirrane:** I am happy to go straight into questions.

[5] **Christine Chapman:** I will start. Obviously, we have read the update from the Minister. I just want to know whether, in your view, enough progress has been made by the Welsh Government in implementing the recommendations of the previous committee's report.

[6] **Ms Kirrane:** Not if you go back to the standards themselves that the previous committee was looking at. It set out a timescale for implementation of the original 2008 all-Wales neonatal standards, so if you are benchmarking against those, I do not think that we are where we should be with all of those standards. In terms of progress against the committee's report, there has been a lot of really encouraging activity, an awful lot of important assessment of where services are, and recommendations about where services need to be going. However, there has been slow progress in terms of investing in services to increase capacity and addressing the nursing shortfall. Where they require money to be spent, that is where the recommendations have really fallen down.

[7] **Christine Chapman:** We will now be delving deeper into the specifics, so I will hand over to Lynne Neagle to look at one of the things that you have already mentioned.

[8] **Lynne Neagle:** Thanks for your evidence this morning; it is very hard-hitting. My questions relate to staffing shortfalls, but before I ask them, there was something that I did not understand in your written evidence. You said that there was a significant shortfall in staffing, and you have highlighted some figures, but later in your paper, where you talk about cot capacity issues, you have said that a fairly modest amount of additional capacity is needed, and that the network has identified that a different distribution of neonatal capacity may be needed. What I did not understand was how the staffing shortfalls seem to be different to the issue of cot capacity, because surely the key issue with cot capacity is the staff.

[9] **Ms Kirrane:** That is a very good point. The issue with cot capacity is that in some parts of Wales there is very low capacity, and in other areas there is very high capacity. However, you are absolutely right that the nursing staff to provide the care for those babies in

the cots is the key thing. At the end of the day, there is a shortfall of around 82 nurses. I suggest that you ask some of the clinicians about the technicalities of some of those points, but we are very clear that the shortage of nurses is the key issue that needs to be addressed as the absolute priority.

[10] **Lynne Neagle:** Is that because the shortage of nurses is in particular places—not geographically dispersed throughout Wales—so there are problems in particular places?

[11] **Ms Kirrane:** There are two things. One is meeting the nurse-to-baby ratios. Babies in intensive care should have one-to-one nursing at all times. For babies in special care, no more than four babies should be cared for by one nurse. More nurses are required to make sure that all units are meeting those ratios at all times. However, on top of that, there is also the issue of occupancy levels of cots. An intensive care ward should be no more than 70% full on average at any time to allow for peaks and troughs. So there are two issues that go hand in hand with capacity. One is the one-to-one nurse-to-baby ratio and the other is the occupancy levels of the cots.

[12] **Christine Chapman:** Lynne, is it okay if I bring Julie in first on this issue and then I will come back to you?

[13] **Lynne Neagle:** Yes, sorry.

[14] **Julie Morgan:** With regard to the peaks and troughs and the number of babies that need neonatal care, you say in your paper that about 4,000 babies are admitted each year, and that is one in nine. Are you able to break it down further? Has the number gone up or gone down?

[15] **Ms Kirrane:** Accurate numbers of admissions have not really been recorded until very recently with the new data system. So, there is no annual national report on admissions. However, we know that there has been an increase in the birth rate, and, according to healthcare professionals working in those units, there has been an increase in admissions in line with the increase in the birth rate.

[16] **Julie Morgan:** Do you think that the percentage of babies requiring neonatal care remains about the same but that it is a larger number because the birth rate is increasing?

[17] **Ms Kirrane:** I think it has increased in line with the birth rate. However, over the past decade or so, more babies have been admitted to neonatal care units and are staying for longer in neonatal care because of medical advances. Those advances mean that babies can be cared for and given successful treatment at much earlier stages of gestation than was the case 10 or 20 years ago. There has been an increase in the number of babies being cared for in neonatal units and they are being cared for for longer periods of time as care gets better.

[18] **Julie Morgan:** So, in relation to Lynne's question, the peaks and troughs are cyclical annual peaks and troughs.

[19] **Ms Kirrane:** Yes. Obviously, it is completely unpredictable when women are going to give birth and, sometimes, units are extremely full and sometimes they are less full over the course of days and weeks. However, the overall picture is of increasing admissions in line with the increasing birth rate. Also, over a long period of time, there has probably been an increase in the number of babies being cared for in neonatal care units due to the earlier stages of gestation at which babies can be successfully cared for.

[20] **Christine Chapman:** Before I bring Lynne back in, I have questions from Jocelyn and Suzy.

[21] **Jocelyn Davies:** I suppose that, in the past, those babies would not have survived. When you talk about capacity being at 70%, what is the average number of cots we are talking about?

[22] **Ms Kirrane:** Do you mean in each hospital?

[23] **Jocelyn Davies:** Yes.

[24] **Ms Kirrane:** The numbers vary greatly. I do not have the numbers to hand, but they vary considerably, from local special care baby units to an intensive care unit that provides care for the sickest babies as well as less sick babies from a certain community.

[25] **Jocelyn Davies:** I guess that these are not big numbers of cots. So, one or two cots can make a big difference when we say 70%.

[26] **Ms Kirrane:** Yes.

[27] **Jocelyn Davies:** Obviously, if you have only 10, it would mean just three cots, and that is your 70%. We are talking about small numbers, not big numbers.

[28] **Suzy Davies:** When you spoke earlier about the number of admissions going up in line with the growth in the birth rate, is the percentage of babies at levels 1, 2 and 3, in terms of the level of care, more or less equal as well, or are there big surges in particular types of care? For example, are there more babies at level 3 than there used to be?

[29] **Ms Kirrane:** I am afraid that I do not have that information, so I cannot say.

[30] **Jocelyn Davies:** I think that we are also seeing more multiple births.

[31] **Suzy Davies:** So, it is likely that there are more babies at level 3 than there used to be, exponentially.

[32] **Lynne Neagle:** On what the health boards are doing to address these shorfalls, how satisfied are you that the action plans that the health boards are meant to have in place are going to address these shorfalls?

[33] **Ms Kirrane:** I have not seen any of those detailed health board action plans on how, specifically, they are going to address the nursing shortfalls. I should say that I am a member of the neonatal network steering group, and therefore I am involved in its ongoing work and see its reviews, paperwork and so on. Many discussions have been held with health boards during the past 18 months at various points as the networks recieved more information about the issues on the ground. The network has been a hive of activity in producing evidence and recommendations to the health boards. It is at that point that I am not confident that the health boards have taken all the required action to take forward the recommendations of the previous inquiry and the all-Wales standards.

[34] **Lynne Neagle:** Am I right in thinking that the network monitors the action plans on a quarterly basis?

[35] **Ms Kirrane:** The network has moved to six-monthly monitoring of compliance against the all-Wales standards.

[36] **Lynne Neagle:** What happens if it finds that a health board has not met the standard in a particular area? What does the network do then?

[37] **Ms Kirrane:** For example, on nurse staffing, the network knows that the standard is not being met, and that that has been the case for some time. It is not that the network expects the health boards to suddenly be able to meet the standard, because we know what the scale of the shortfall is. Therefore, the discussion with the health boards revolve around what their longer-term workforce planning is, what the training plans for nurses are and so on. So, it means longer-term discussions.

[38] **Lynne Neagle:** So, the network does not have to report that to the Minister and say, 'They are not making the grade in this area'.

[39] **Ms Kirrane:** The reporting pattern, as far as I understand it, is that the network is set up in an advisory role to the health boards through the Welsh Health Specialised Services Committee, which, in turn, advises the Minister. So, the network does not report directly to the Minister, and the network does not have the authority to instruct the health boards to take any particular action.

9.30 a.m.

[40] **Christine Chapman:** Thank you. I want to move on to issues around training.

[41] **Jocelyn Davies:** Just as a follow up and a lead-in to my questions, do you find the local health boards open and transparent in relation to their planning?

[42] **Ms Kirrane:** As I say, I have not had any personal contact with the health boards at this stage. Given the relationship between the network and the health boards, which I have just explained, and as I make clear in my paper, it would be very useful for the committee to ask to see the health boards' individual plans directly and for those to be made available to the public.

[43] **Jocelyn Davies:** Okay. So, they are not routinely made available to the public.

[44] **Ms Kirrane:** Not that I am aware of.

[45] **Jocelyn Davies:** We have the all-Wales framework for neonatal nurse training, which has been developed and circulated to the local health boards. What would you expect to happen now?

[46] **Ms Kirrane:** Sorry, can you repeat the question?

[47] **Jocelyn Davies:** The all-Wales framework for neonatal nurse training has been developed and circulated, so what do you expect will happen now?

[48] **Ms Kirrane:** I would expect that the health boards would—well, it is a complicated question really, but—

[49] **Jocelyn Davies:** Okay then, what do you hope will happen?

[50] **Ms Kirrane:** Is that around the training available for nurses? I am not quite sure which paper you are referring to.

[51] **Jocelyn Davies:** Yes.

[52] **Ms Kirrane:** If the paper recommends that training is required, then there needs to be support for the service to allow nurses to be released to go into training. I know there are

particular issues because services are so overstretched, and there are some serious issues in terms of their units' ability to release nurses to go for training.

[53] **Jocelyn Davies:** How many advanced neonatal nurse practitioners do we have, and how well are they being utilised?

[54] **Ms Kirrane:** I do not know how many there are in Wales; I do not think there are very many. This is a really important area for development for the future, partly as a career pathway for nurses, but also because we know there are going to be a lot of issues in terms of medical staffing in the not too distant future. Advanced neonatal nurse practitioners can work on the medical rota and therefore take some of the medical roles.

[55] **Christine Chapman:** I will move on to medical staffing now. Mark, do you want to start?

[56] **Mark Drakeford:** Thank you very much indeed. In your evidence, Helen, you report a shortage of junior doctors and difficulty in staffing middle-grade rotas, which we know are wider problems within the Welsh NHS, and we are familiar with some of the reasons for those problems. However, you specifically say that a drastic reduction in the number of trainee slots is expected from 2014. I wondered three things about that. First, can you tell us more about the evidence for that? Secondly, why do you think that is the case, and thirdly, if that is the case, what impact will that have on future provision?

[57] **Ms Kirrane:** The evidence for that is a paper from the Royal College of Paediatrics and Child Health to the network, and I know that you are seeing a representative from the RCPCH today. My understanding is that that is in line with the RCPCH's review of services published last year, called, 'Facing the Future', which identified that, although there had been a large increase in the number of paediatricians across the UK over the last decade or so, that increase was not enough to provide enough doctors for each hospital. The right training was not necessarily available for doctors so, basically, the RCPCH recommended that the number of hospitals providing paediatric care is reduced. That is what the college is suggesting as the way forward.

[58] **Mark Drakeford:** So, in a way, that is a professionally driven set of decisions on how the profession itself thinks that professional training is best organised and delivered. That is helpful.

[59] I have one other question on this. If a service that is, essentially, staffed and led by middle-grade doctors will not be sustainable in the future, we have heard suggestions that it should move towards being a consultant-delivered service. Do you think that that is a good idea? If so, what are the implications for the rest of the architecture that would lie beneath it?

[60] **Ms Kirrane:** That is quite a technical question about a clinical service, which I do not have that much information about. There are implications of moving to a consultant-led service, both positive and negative. It is positive in that consultants have the most experience and are able to give junior doctors the best training and supervision. However, with regard to attracting doctors into the profession, knowing that they will have a life-long career of being on call is an issue. My understanding is that that is accepted as the best way forward by the community to provide care for babies.

[61] **Suzy Davies:** My question develops that idea, and is on the Betsi Cadwaladr University Local Health Board. You say in your written evidence that the intensive care units at Ysbyty Glan Clwyd and Wrexham Maelor Hospital are nowhere near approaching compliance with the all-Wales neonatal standards. Why do you think that? Why do these matters need to be addressed without delay? What are your specific concerns about Betsi

Cadwaladr?

[62] **Ms Kiranne:** The two hospitals that you mentioned are providing long-term intensive care to babies without the staffing required to provide that care. The guidelines state a certain level of staffing to provide a safety net for babies. The standards are very much based on what is safe care.

[63] **Suzy Davies:** Are you able to say—I appreciate that you may not be able to do this—what specific deficits exist? Which particular type of nurse or doctor is missing in their mix?

[64] **Ms Kiranne:** One particular issue is the shortfall of consultant neonatologists. There is only one consultant neonatologist for the whole of north Wales. Although funding was made available for a second consultant neonatologist as part of the transport service, there were problems recruiting at the time, partly as a result of uncertainty about if and where there would be an intensive care unit in the long term in north Wales. It is my understanding that, for any unit to operate as a neonatal intensive care unit, it needs a full rota of approximately eight consultant neonatologists to provide the right level of cover at all times. You can see that north Wales is falling well short of that. Also, I understand that there is no separate rota for middle-grade doctors, which means that the middle-grade paediatricians are covering the general paediatric unit and the neonatal units. That means that they are obviously not available to provide hands-on care and supervision at all times. There is also a larger shortfall in nurses in the north Wales community than in any other community in Wales. So, across the board, the staffing issues are very serious.

[65] **Jocelyn Davies:** Clearly, you know that there are shortfalls elsewhere, but this is the only one that you have pointed out in your recommendations. So, the situation there is exceptional—from what you have told us, it is dire and unsustainable. You say that there are shortfalls elsewhere, but that this one is exceptional.

[66] **Ms Kirrane:** There are shortfalls elsewhere, but this one definitely stands out.

[67] **Suzy Davies:** I was going to asking about the other three families, as there are obviously problems there, but they are not quite as bad as this one. There is a review going on at Betsi Cadwaladr at the moment; are you confident that it will highlight the problems that you have drawn to our attention and come up with solutions to resolve them?

[68] **Ms Kirrane:** I have seen the reviews that were done by groups of clinicians, and they identified very similar issues. So, in the early-stage reviews that identified the need for a proper review in north Wales, they seemed to be very concerned about the same issues. However, there has been a delay in getting any recommendations towards public consultation. My understanding is that that is because a number of services are under review in north Wales, and not just maternity, neonatal and paediatrics. It is my understanding that the health board needs to bring all those reviews together at the same time.

[69] **Suzy Davies:** You have led me to my final question, in a way. I appreciate that you have not seen all of the evidence that we have received—not the written evidence, at least—but it strikes me that we have a plethora of reviews, recommendations and reports and all manner of exciting things; has anything actually happened as a result of them, as far as you can tell, in the form of improved services?

[70] **Ms Kirrane:** Obviously, the introduction of the transport service has been a very important development.

[71] **Suzy Davies:** There will be some questions on that later.

[72] **Ms Kirrane:** Also, there is the introduction of the network to co-ordinate care properly across Wales and to have oversight of what is going on in the units. Both have been very important developments that have happened since the last inquiry.

[73] **Lynne Neagle:** Your evidence on Betsi Cadwaladr is very worrying. Has the network been able to pick this up? You may not be able to answer this—I know that you are just one representative on the network—but if the network knows that there are serious safety issues in one area, has it fed those concerns in to WHISC? If the network is monitoring this, albeit in an advisory capacity, how have those concerns been taken forward?

[74] **Ms Kirrane:** The network has definitely shared those concerns with the health board and with WHISC. That has been taken into account in the review of the health board in north Wales.

[75] **Jocelyn Davies:** I think that you have been very charitable in the way that you have expressed your concerns today. How long has this been going on?

[76] **Ms Kirrane:** A review was conducted in 2005, if I remember correctly, which identified that an investment of £10 million was required in services to ensure their compliance with the nursing standards and the other core standards for premature and sick babies. Not much action took place at that time or for a number of years after that. Then, in 2008, the all-Wales standards were introduced, and the £2 million per annum investment into the transport, network and information system was announced. So, that service was deliverable towards the end of 2010 to 2011. It has taken a long time. It is just one part of the service; the transport service is a small part. The 2005 review identified the shortfall in nurses, and we have known about it for a long time. There just has not been the investment since that time to address those issues.

9.45 a.m.

[77] **Julie Morgan:** I want to ask you about therapy and access to the allied professions. You say how vitally important they are, but you also refer to the fact that access is pretty limited and that only three out of 12 units have the right access to physiotherapy, for example. What can be done about this and what are its consequences?

[78] **Ms Kirrane:** Access to therapies is one of the all-Wales neonatal standards from 2008. More detailed standards have also been produced by the clinical community for neonatal care, namely by the British Association of Perinatal Medicine, in 2010. The network conducted an audit of therapy provision and, as you said, the feedback was that access is extremely patchy. Physiotherapy is the only element of those services in which the standards are fully met. In other therapy services, such as speech and language therapy, which help to assess swallowing and so on, are very important to ensure that neonates are feeding properly, dietetics, which similarly deals with nutrition for babies, and occupational therapy, access was very patchy. No dedicated professionals were available to neonatal services; no dedicated time was given to neonatal services. Babies were being referred to general therapy services, so they were reliant on services being available. There was no designated time for neonates and there was no real evidence that any of those therapists had the required skills and expertise to deal with extremely small and very vulnerable babies. Access to the right level of trained therapists is an issue that needs to be looked at.

[79] **Julie Morgan:** I have two follow-up questions. In your response, did you say that all of the neonatal units were compliant with the physiotherapy standard, because that is not what you say in the evidence?

[80] **Ms Kirrane:** No, I am sorry. What I meant to say was that I believe that three units

are fully compliant with that standard.

[81] **Julie Morgan:** Can you tell us what the consequences are for these babies if they do not have access to physiotherapy and all the other allied professions?

[82] **Ms Kirrane:** As I mentioned earlier, more babies are surviving, but it is vital that we ensure that babies have the best possible outcomes. Any feeding issues that might mean that they are undernourished, or if they are not able to take breastmilk, need to be addressed, and they can be successfully addressed with the right care. Breastfeeding is important in terms of nutrition for babies, but it is also important for the bonding of mothers and babies. So, it is vital that not only is the survival of babies addressed—

[83] **Julie Morgan:** It is about their quality of life, basically.

[84] **Ms Kirrane:** I am not saying that babies have a worse quality of life, but they certainly have a requirement for those therapies and they should be getting them.

[85] **Julie Morgan:** Is there any monitoring of what happens if they do not get the required help?

[86] **Ms Kirrane:** The monitoring of babies' outcomes has been a bit patchy across the whole of the UK. We have been calling for better monitoring so that we know how babies are doing a couple of years down the line. I do not know what action the network has taken on the monitoring of babies' outcomes, but that is an important area to be addressed, from Bliss's perspective.

[87] **Lynne Neagle:** The question of access to the therapies is not only about when they are in the unit, is it? Your paper says that it is within a timescale of one to three years. For some reason, these babies are not being picked up by those services when they leave the neonatal unit. Is that right?

[88] **Ms Kirrane:** Yes, I believe so. One of the key services is neonatal community outreach nursing. It links in with cot capacity, really; many babies could be discharged earlier from care if there was more support for them in the community. That is where better access to community outreach nurses would really help by getting babies discharged from hospital sooner, thereby freeing up cots and resolving some of the staffing issues there. It would also mean that the babies were back at home with their mums, dads, and families. So, as well as the therapy provision, community outreach nursing is something that needs to be invested in as well.

[89] **Eluned Parrott:** You talk in your evidence about shortages of medical and nursing staff resulting in considerable clinical risk and cot closures in neonatal units. In fact, I think that you said that babies are being put at risk by standards not being met. Are you aware of any studies, or do you have any evidence, that demonstrate that there have been preventable baby deaths or that the clinical outcomes for babies who are being cared for in services that are not meeting the standards are less healthy than those for babies in other units?

[90] **Ms Kirrane:** There is definitely a range of studies that support that statement. One study, for example, highlighted that, for babies in intensive care, a minimum of one nurse caring for them at all times would reduce these babies' risk-adjusted mortality by almost 50%, which means that when babies' individual health problems are accounted for, that one-to-one nursing would reduce the chance of death by 50%. So, that is a very strong piece of evidence. There is other evidence that details for how much time a nurse needs to be present to provide the right care for babies. There is other evidence that states that babies are not getting the right intervention at the right time because of a shortage of nurses. I would be happy to

provide those references to the committee when I get back to the office.

[91] **Eluned Parrott:** Indeed. I would be particularly interested to know whether there are any studies that have compared those standards and that evidence with the situation on the ground in Wales to see the scale of the problem and to ascertain whether Welsh babies are dying as a result of the availability.

[92] **Ms Kirrane:** I am not sure whether any of those studies looked at the situation of babies in Wales. The same care is being provided across the UK, essentially. Babies have the same health problems elsewhere in the UK, so the studies stand up as much in Wales as they would anywhere else in the UK.

[93] **Eluned Parrott:** Taking it forward, obviously we need to understand what changes we need to effect in order to ensure that these services are safe and giving babies the best possible health outcomes. What steps do you think need to be taken?

[94] **Ms Kirrane:** As I have highlighted, I think that there needs to be an improvement in the accountability of the health boards in terms of understanding what action they are taking to address the shortfall that everybody is clear exists, and which has been highlighted in numerous reports and inquiries. It is really important that the health boards are able to make clear to their public how they are going about improving care for these babies.

[95] **Eluned Parrott:** Looking at your evidence, you talk about the all-Wales neonatal network, and discuss the idea that a different distribution of neonatal capacity is needed, because there are some areas that are over-capacity and others that are under-capacity. Therefore, you do not necessarily have the critical mass and expertise to care for the babies, and it is a poor use of resources that could be better used elsewhere. Do you agree with that? In what way could we encourage that redistribution to be taken forward?

[96] **Ms Kirrane:** I do agree with that, because we are not in a situation where money is freely available. There is an urgent need for those areas of care that are highly over-capacity to support those that are over-occupied and understaffed. There is an absolute requirement, really, for resources to go into those areas. Money does not grow on trees, so we have realistic requests about how money should be spent. There is evidence that shows that babies' care is better in larger, more regional centres with more expert staff, particularly for the sickest babies, in intensive care, which is why we would not, in theory, oppose the downgrading of a unit to a lower level of care, or even looking at whether it was necessary for there to be a unit in every area where they currently exist.

[97] **Eluned Parrott:** Presumably, you would only approve of the downgrading of one unit if those higher level resources were transferred to a regional centre elsewhere.

[98] **Ms Kirrane:** Absolutely. It is not about reducing access; it has to be provided in the right place, by the right professionals, with the right skills. In the context of ensuring that babies have access to services that can meet the minimum standards that ensure their best possible chances and their safety, we would not oppose any service review or reconfiguration.

[99] **Christine Chapman:** I have one question from Julie Morgan.

[100] **Julie Morgan:** It was just a general question arising from Eluned's questioning. If medical advances are to continue, and we hope that they will, because it is fantastic that these babies now have a chance of survival, that obviously raises an issue—that is, the strain on the actual provision is very great.

10.00 a.m.

[101] Do you have any ideas about how that can be addressed in a more global way? Obviously, you are close to all this and watching it and it seems that there is a big challenge for the health service. We can ask about all the nitty gritty and how each part will cope—that is really all we can do, I suppose—but in the context of improving medical science, how are we going to work out the resources?

[102] **Ms Kirrane:** I think that it requires a bit of bravery in terms of addressing where services should be provided. There is a real need for patient groups such as ours, health professionals, politicians and health boards to come together and understand what arrangement of services can realistically provide the right level of care for babies. That is one answer to that question. Another important thing, which Bliss is heavily involved in, is family-centred care. Families that are fully involved in the care of their baby can free up some of the nurses' time to look after other babies. Parents are not always encouraged to feed their baby or change their nappy or clean them. A lot of that is often done by nurses and parents often report feeling as though the baby is not theirs because they are being cared for by medical professionals when it could often be done by the family. Ensuring that services are provided fully involving the families can actually—

[103] **Julie Morgan:** Is that a general issue?

[104] **Ms Kirrane:** Yes. It is not an issue that Wales stands out on compared to other parts of the country, but Bliss is very pleased that the network is going to be working with us in the coming year to look at introducing the newly published Bliss baby charter audit. That will go through a series of recommendations from Bliss about how services can put families at the heart of babies' care and at the heart of decision making about what care those babies should receive. That is an important innovation that really needs to happen.

[105] **Jocelyn Davies:** The further away the service is, the less likely you are to be able to go to change your baby's nappy, particularly if you have other children. In terms of the redistribution of provision, can you cite one example of where that has happened between local health boards? Where there is one local health board with over-provision, do they ever give up provision in favour of another local health board? Or, if it found that there was over-provision, would it probably have something else that it wanted to spend that money on?

[106] **Ms Kirrane:** I do not have any evidence of that. I do not know of that happening. The point you raised about the impact on families of services being more centralised is a really important one. Alongside any changes to services that might happen to increase safety of care for the babies, they need to address any extra support required by the families in terms of overnight accommodation. It is a huge financial drain on families to travel long distances to see their babies in hospitals that are a long way from home, particularly if they have other children at home. It is a huge financial, practical and emotional strain on families, so some serious thought needs to go into that when looking at services.

[107] **Eluned Parrott:** Sadly, in reality, the way it works is that it is the patients who are sent into other health board areas rather than the provision, meaning that those individuals have to take the strain resulting from patchy availability. I have seen patients being sent from one unit to another, and told, 'Sorry, we have run out of space'. When I was in hospital myself I saw it happening. The question that I have is one of realism. What practical things could we do to help the health boards work more collaboratively, because the evidence is that they do not at the moment?

[108] **Jocelyn Davies:** That is probably beyond—

[109] **Ms Kirrane:** I cannot speak for the health boards.

[110] **Christine Chapman:** No, but I am sure that we will come back to those issues. Keith Davies will now ask a question.

[111] **Keith Davies:** Cyn gofyn fy nghwestiwn, hoffwn barhau â'r drafodaeth a gawsom yn gynharach. Rwy'n cofio mam-gu yn fy etholaeth a'i hwyres, a oedd yn faban bach, a oedd mor sâl y bu'n rhaid iddi fynd i Fryste, oherwydd mai yno roedd yr arbenigedd. Nid oedd neb yn cwyno am hyn oherwydd roeddent eisiau'r gorau i'r baban. Rwyf wedi darllen yn rhywle bod angen 2,500 o enedigaethau mewn ardal i gael uned arbennig. Os ydym yn sôn am gydweithio rhwng y byrddau iechyd, dylem edrych ar dde Cymru a gofyn faint o enedigaethau sydd yn ne Cymru, rhannu'r swm hwnnw â 2,500 gan weld faint o unedau arbennig sydd angen arnom. A oes gennych unrhyw sylwadau ar hynny?

**Keith Davies:** Before I ask my question, I would like to continue the discussion that we had earlier. I remember a grandmother in my constituency and her granddaughter, a little baby, who was so ill that she had to go to Bristol, because that is where the expertise was. No-one complained about it, because they just wanted the best for the baby. I have read somewhere that you need 2,500 births in an area to have a special unit. If we are talking about collaboration between the health boards, we should look at south Wales and ask how many births there are in south Wales and then divide that sum by 2,500 to see how many special units we need. Do you have any comments on that?

[112] **Ms Kirrane:** I am not aware of the correct number. I have not heard of that statistic, but you are right that they have to look at the population, at mothers and births, and work out roughly what the right level of provision should be in an area, across the health boards.

[113] **Keith Davies:** Mae hynny'n bwysig oherwydd bod pob bwrdd iechyd yn awr yn sôn am strategaeth newydd erbyn diwedd eleni, felly mae'n bwysig bod y pethau iawn yn y lleoedd iawn. Dyna'r cwbl rwy'n dweud am hynny.

**Keith Davies:** That is important because every health board is now talking of new strategies to come in by the end of this year, so it is important that the right things are in the right places. That is all I will say about that.

[114] Yn adroddiad y pwyllgor blaenorol, a bu i chi sôn am hyn, mae sôn am y gefnogaeth i rieni. Y dystiolaeth a gawsom oddi wrth y Gweinidog oedd ein bod yn gwneud cynnydd da ar yr argymhellion a oedd yn yr adroddiad blaenorol, sef hyfforddiant a chefnogaeth i rieni ac o safbwynt rhoi lle iddynt aros. Os yw'r plentyn yn yr ysbyty am fis, neu am ba bynnag hyd mae'r plentyn yno, dylai fod cyfle i'r rhieni aros yn yr ysbyty. Mae'r Gweinidog yn dweud ein bod yn gwneud cynnydd da i weithredu'r argymhellion hynny. Rwy'n teimlo y bu i chi ddweud yn gynharach efallai nad ydym yn gwneud y cynnydd y mae'r Gweinidog yn sôn amdano.

In the previous committee's report, and you mentioned this, support for parents is mentioned. The evidence that we had from the Minister was that good progress is being made on the recommendations in the previous report, namely on training and support for parents and on providing a place for them to stay. If the child is in hospital for a month, or for however long the child is there, there should be an opportunity for the parents to stay in the hospital. The Minister is saying that good progress is being made on implementing those recommendations. I feel that you said earlier that we are perhaps not making the progress that the Minister is talking about.

[115] **Ms Kirrane:** I am not aware of any particular progress that has been made in terms of increasing accommodation for families, for example. The network, in its recommendations to health boards, has had many different things to look at, such as nursing, medical staffing, therapy provision, transport services and data systems—I could go on. The network has always identified that it wants to look at provision for families, and it is getting quite

impatient to look at it. With Bliss now having produced its baby charter audit, we have an off-the-shelf assessment tool that the units and the networks can use to assess whether units are providing the right care and support for families. That is a really important starting point to see where the major issues lie for families. It is a really critical time to be assessing that support for families. We are looking at new strategies being introduced, a possible maternity service, and other service reviews taking place across Wales, and it is important to ensure that we understand what provision and support there is for families before any changes can be made.

[116] **Christine Chapman:** Do you have another question, Keith?

[117] **Keith Davies:** No.

[118] **Christine Chapman:** Okay. I remind Members that we have around three minutes left, so I ask you to be as concise as possible. Suzy, do you want to come in?

[119] **Suzy Davies:** Yes. I will keep it brief. You say in your evidence that the implementation of the all-Wales neonatal standards remains a low priority for health boards. How confident are you that that will change in the future?

[120] **Ms Kirrane:** That is my perception. I have not had those discussions with health boards, but it appears to me that that is where the issue lies now really. They have been provided with the evidence of what the problems are, and it would be fair to say that, at best, progress has been slow in terms of them bringing any changes about. So, I do not know how confident I could be that it will be made a higher priority for health boards. That is why I am encouraging the committee to do all that it can to raise the profile of this issue and ask the health boards to provide information to the public about how they are going to meet the standards and work towards meeting those standards.

[121] **Suzy Davies:** Thank you; that is a very clear aspiration.

[122] **Christine Chapman:** I will just finish by asking you, Helen, if there was just one recommendation that you had for the committee, whether there would be one that you would prioritise above all others.

[123] **Ms Kirrane:** The main issue remains the shortages of nurses across Wales, so that is the area that needs focus and prioritisation. The health boards are the bodies that decide where resources go and how services are planned and funded. Ensuring that there is an understanding of how much of a priority addressing this shortfall is, would be my No. 1 recommendation for the committee.

[124] **Christine Chapman:** Thank you very much, Helen, for your very comprehensive evidence. It is obviously a very complex issue, but a very important one as well. So, thank you for attending this morning. There will be a transcript of today's meeting and we will send it to you to check for accuracy. Thank you very much for attending.

*Gohiriwyd y cyfarfod rhwng 10.14 a.m. a 10.29 a.m.*
*The meeting adjourned between 10.14 a.m. and 10.29 a.m.*

## Ymchwiliad i Ofal Newyddenedigol—Sesiwn Dystiolaeth 2
## Inquiry into Neonatal Care—Evidence Session 2

[125] **Christine Chapman:** I will introduce our next witnesses, who are Lisa Turnbull, policy and public affairs adviser for Royal College of Nursing Wales, Dr Jim Richardson,

RCN Welsh board member for children and young people, and Pamela Boyd from the Neonatal Nurses Association. I welcome you here today to provide evidence. The Members will have read the papers, so, if you are happy, we will go straight into questions.

[126] I will start with a broad question. In your evidence, you highlight your concerns about the shortfall in neonatal nurses. Are you satisfied that the action being taken by the health boards to address the serious neonatal nurse staffing shortages is adequate and timely?

10.30 a.m.

[127] **Ms Turnbull:** The short answer is 'no', as we are still very concerned. There is a clear shortage of qualified staff with the necessary skills on the wards. One of the things that we are very concerned about is that action has not been taken to address the fact that one of the underlying causes of this is the need to provide education to ensure that you have sufficiently skilled people who can then apply for the posts. So, one issue is the LHB creating those posts, and in sufficient number. For the underlying issues, you need to ensure that you have the number of people in the profession who are able to apply for and take up those positions. We do not feel that either of those courses is being sufficiently addressed in Wales for neonatal nursing.

[128] **Dr Richardson:** Also, it represents a confining factor in terms of the education of neonatal nurses because, when the staffing is inadequate, release is difficult. It is a twin factor that is acting as a constraint.

[129] **Ms Boyd:** The point of view of the Neonatal Nurses Association is that we would like to see everyone who works in neonatal care qualified in that specialty. So, you need to free them to go on to neonatal modules and the advanced practitioner courses, if they so wish, and have a designated career pathway, so that you retain staff, as well.

[130] **Lynne Neagle:** We heard from Bliss, prior to your coming in, that its view is that the shortfall is down to a lack of funding. You are saying that you think that it is more complicated than that. Are you able to quantify to what extent it is a lack of funding and to what extent the problems with training nurses in that specialty are a factor?

[131] **Ms Turnbull:** The main cause is the lack of funding because, unlike professions in other areas, it is not a case of people not wanting to go into the profession. There is no shortage of nurses who would like further training, further skills and further qualifications, so there is no lack of demand. The problem is with the availability of that education and training, and being released from a post to be able to do that. Crucially in nursing, there is no built-in guarantee of any kind of further education or training. So, many of our members, even those who are struggling, are doing this in their own time and with their own money, and it really is a precarious situation. There does need to be a much more strategic addressing of the need to release people and train them and then to create the posts that are needed.

[132] One of the issues that we have highlighted in the paper is, for example, the lack of advanced nursing skills, which would be one way of addressing some of the problems created by the lack of medical cover.

[133] **Lynne Neagle:** Thank you for that. There was something in your paper that I was a bit confused about. On page 13, you say that there is too much level 2 care in each location, because it has been reduced to making only level 2 available, because there are not sufficient advanced specialist nurse practitioners and medical staff. Further on in the paper, however, you say that it is clear that, because not enough level 2 places are available, level 3 cots are being taken by babies that do not need level 3 care. I was a bit confused by that, because it seemed contradictory.

[134] **Ms Turnbull:** Apologies for the confusion. What we are trying to convey is that there is a lack of capacity at both level 3 and level 2. Given the lack of capacity at both levels, what we are hearing from our members is that people are struggling and putting the baby in any available place rather than in the most appropriate place. This then creates huge difficulties with people moving around. One story that I heard this week from a nursing member was about a mother and baby who had to travel from Haverfordwest to Gloucester, from Gloucester to Carmarthen, and from Carmarthen back to Haverfordwest. That was a very long journey, and it was obviously a very distressing time, but it is an example of something that has been created by the fact that places are being filled in very difficult circumstances, which lead to these kinds of problems. So, the answer to your question is that we feel that there is lack of capacity at both levels, and both levels are needed; it is not a case of one or the other.

[135] **Lynne Neagle:** Bliss told the committee that the service in Wales was too reliant on nurses graded band 5 and below. Would you agree with Bliss on that and do you think that that leads to an inappropriate skill mix?

[136] **Ms Turnbull:** Yes. There needs to be development of nursing posts at the higher, more advanced level, and at all levels. Part of the issue, as we said, is that in the education commissioning process the needs of the neonatal service need to be looked at again and to take a higher priority on that.

[137] **Lynne Neagle:** Do you know, and you may not, whether the health boards have included plans to deal with these educational issues in the plans that they are developing?

[138] **Ms Boyd:** I cannot speak about the position nationally, but we have a structure where new band 5s come in, namely newly qualified nurses, whether they are paediatric nurses, general nurses or from a midwifery background, and then we have a designated career pathway. We start them off at the special care level, we support them, we bring them up to a certain competency level, we move them on to the high-dependency level, and the plan for the future is that when they are at that level of competency where we think that they are all-singing, all-dancing HDU nurses, we will move them into the ITU. That is how we see their career progression, backed up by education in modules—if they want to go on to the R23 in the future, they can see what they need to do to be a highly skilled neonatal nurse. As well as the practical skills, we need the education to back them up with theory, so that we give a good-quality service. You can come into nursing neonates from the fields of adults, paediatric or midwifery, and you will start at that level, but you need to progress from that level, and you will need the education to back it up.

[139] **Ms Turnbull:** Theoretically, when the local health boards produce their recommendations around education commissioning, they should take into account the needs of the neonatal service. What we are saying is that, from the outcome, we do not feel that a high enough priority is being given to it. If you look at the maternity or midwifery service, you will see that there has been a recognition that the birth rate has changed and the demographics are changing and that we need to address that in relation to the healthcare professions. That may have been done for midwifery, but we now need to carry that over into looking at neonatal care.

[140] **Dr Richardson:** We have made progress in Wales in terms of the provision of neonatal nurse education. A much more coherent offer assists in preparing the middle grade neonatal nurses of the future, because that traditionally has been the problem, namely allowing people to progress through a career trajectory. However, again, the concrete support for that from the Government and the health boards is very important for sustaining it.

[141] **Julie Morgan:** Lisa, you have already mentioned the fact that nurses have to use their own time to do training. Can you expand on that a bit? How widespread is the issue of nurses having to use their own time? Also, can you expand on the funding?

[142] **Dr Richardson:** It is a patchy picture, generally. Each university has post-education contracts with the stakeholder health boards, so there are some dedicated funds to support that. However, health boards outside of that area have to identify funds to support education. In times of financial constraint, it becomes more common for nurses not only to have to fund their education themselves, but to undertake it in their free time.

[143] **Julie Morgan:** So, that is common.

[144] **Dr Richardson:** Yes.

[145] **Julie Morgan:** The Minister for Health and Social Services has told us that the all-Wales framework for neonatal nurse training has been developed and has gone out to local health boards. Do you feel that this is adequate in addressing the needs?

[146] **Dr Richardson:** Yes, certainly. It is a recent development, as I said earlier, but a coherent approach has been taken to this particular form of nurse and midwife preparation. A good deal of work has gone into it, and Welsh clinicians have been particularly active in developing these standards. They will serve as a route map for the future in terms of the provision that has to be in place.

[147] **Ms Turnbull:** I would add, however, that the Royal College of Nursing generally, not specifically in relation to neonatal nursing, has grave concerns about the way that safe and evidence-based staffing levels can fall down in practice, and are falling down in practice, and the impact of that on safety and the quality of care. Therefore, we have consistently argued that there needs to be some kind of clear and explicit statutory duty on local health boards to demonstrate how they are looking after safe, high-quality workforce planning. We believe that that is an important way forward, because setting out professional standards is obviously incredibly important and has to be done. It should be evidence based, and so forth. However, if they are merely the professional standard but there is no requirement, or they are not inspected against or regulated, then that means that, when times are hard, they may very well be the first thing to go.

[148] **Jocelyn Davies:** I have a question regarding your suggestion that it should be a statutory requirement. Surely the local health board would want to have safe services. That was not really a question. [*Laughter*.] The proposal that we would need to have legislation would give me grave concerns about the local health board accountability, if you are saying that we need legislation in order to have safe services.

[149] **Ms Turnbull:** I do not want to get off topic too much, but I will say that, broadly, we have unfortunately seen situations in England where service providers have fallen down on this issue, with tragic consequences. The Royal College of Nursing is saying that we need to take every step possible to ensure that the situation does not occur in Wales. One way of doing that is to be explicit about statutory duties, and inspect and regulate against them. That is our suggestion for the way forward.

[150] **Ms Boyd:** Most units tend to use the British Association of Perinatal Medicine standard of one-to-one care for ITUs. It happens, but it is sporadic; you aim for the best care, but there are situations where you cannot always provide that. I know that many of our association members worry that, when someone comes in through the door and we deal with them, we give the best that we can, but are we safe, and are we safe in each shift, not just that moment in time, but the next shift and so on? It is a worry and it does happen.

[151] **Jocelyn Davies:** So, minimum standards could be laid down in some sort of enforceable document.

[152] **Ms Turnbull:** They should be appropriate standards, rather than the minimum. I would like to echo the last point. Having talked to quite a few of our members in preparation for giving evidence today, the frustration and stress came across clearly during the phone calls. I talked to one lady who said that, for her shift the next day, there should be two qualified nurses, but she had been told that there would be just her and an unqualified healthcare support worker. So, the pressure is already on her before she even goes in for her shift, because she is wondering what will happen and how she will cope with that. So, I would like to echo the real impact on the morale of the workforce in the sense that they constantly feel under siege and are constantly worrying. Things may be fantastic, but you are constantly worrying that something may happen that will cause a problem.

[153] **Ms Boyd:** You are in firefighting mode; it is an unpredictable service because you do not know what is going to come through your door. With the cot locator system, you may now have babies coming from other areas who have more complex needs than your unit may be used to, but you have to deal with it. So, neonatal nurses are always in firefighting mode even if everything is going very well. At the association's conference last year, I spoke to nurses from all over the UK and it appears that everyone is saying the same thing, so it is not just a local issue, it is a national issue.

[154] **Christine Chapman:** Okay. Suzy has a supplementary question.

[155] **Suzy Davies:** We heard evidence from Bliss just before you came in and, at the risk of duplicating what has been said, I just wanted to check that we were all talking about the same thing. Bliss highlighted that it had concerns that the implementation of the all-Wales neonatal standards remained a low priority for health boards. Is that what you would like a statutory duty in connection with? Am I mixing up my standards?

10.45 a.m.

[156] **Ms Turnbull:** They are connected. We were making a broader point about the provision of safe care for patients across all areas. So, when we talk about statutory duty, the Royal College of Nursing has been talking about a duty across all areas; we have not been talking about a specific one. However, if there was such a duty, you would expect each speciality, such as neonatal care, to look at the evidence base, the professional standards and at what is acceptable. Those standards are the ones that you would look to in neonatal nursing.

[157] **Jocelyn Davies:** We have heard that earlier discharge from units would be beneficial, due to capacity and nursing shortages and so on, and that babies would do better at home with their mothers and that there would be better outcomes. However, that would require adequate outreach nursing. Are multidisciplinary discharge planning and neonatal outreach teams available across all 13 units?

[158] **Ms Boyd:** I cannot say, hand on heart, that that is the case across all 13 units. My unit has a multidisciplinary outreach service, and we try to discharge babies home with a good support team. However, given the rise in the birth rate and that babies with more complex conditions are surviving, I do not know what outreach services are available. For example, babies are brought to south-east Wales and then return to west Wales, so what outreach services are available for them? Will they end up staying in hospital longer, because that area cannot provide monitoring of oxygen for babies at home? How far will they have to travel for their follow-up specialist clinics? There are rural parts of Wales that need to be looked at in

terms of outreach support for babies and parents.

[159] **Ms Turnbull:** Many of our members were envious of the community outreach service and said that they want to see that develop in their area, because they felt that it was an innovation that would, ultimately, assist in the way that services are delivered.

[160] **Jocelyn Davies:** That would involve keeping babies at home rather than having to go back into hospital, perhaps. What level of qualification would you recommend for that outreach nursing?

[161] **Ms Boyd:** You would have to be qualified in a speciality. Are there specialist community liaison service courses and home oxygen courses?

[162] **Dr Richardson:** Yes. There is a combination of provision that is available to nurses undertaking these sorts of roles. The specialist modules in neonatal care are important, but there are also modules available on community care, because providing care in someone's home is very different to the context of a structured hospital environment. We have identified that transitions in care are a pinch point in virtually all services, but it becomes complex with neonatal care, because parents are taking on care roles that we would not have envisaged a decade ago. So, we are also looking at equipping people with the knowledge and skills to manage the subtleties of transitions in care. It is that package that needs to be put together for the nurses who identified that as their career pathway.

[163] **Julie Morgan:** One thing that Bliss said was that some parents felt unable to be as involved in the care of their babies in hospital as they would like to be, in terms of changing nappies and feeding. Do you have any evidence of that?

[164] **Ms Boyd:** We are all trying to move towards more family-centred care. Ideally, we would want parents to change nappies, provide oral care and kangaroo care and be there at the incubator reading a story to their baby, perhaps, but we are confined by the type of condition that the baby has and the space and facilities available for parents to feel comfortable. There is an issue with space to move around, especially with cot occupancy as it is, and older hospitals have limited space. When you outgrow your space, parents may feel uncomfortable and feel that they are in the way and that they are getting on the nurses' nerves. That has a huge impact on them. We should look at improving family services so that parents feel that they are a part of the care, rather than feel that they are in the way because they are in a hospital. Over the years, we have tried to move away from that, but we still have a way to go.

[165] **Dr Richardson:** I would say that that is part of an important evolution in the philosophy of care that we have seen over the past decade in particular. All education provision is now underpinned by the values of baby-centred care in a family context. Parents are offering care to their very fragile babies that I would not have imagined at the beginning of my career. It is sometimes highly complex technical care—but fully hands-on care—across the whole range of the baby's needs. Neonatal nurses are embracing and facilitating that as the educational level is secured.

[166] **Julie Morgan:** Obviously, that helps with going home.

[167] **Dr Richardson:** Yes, it does.

[168] **Lynne Neagle:** I have been working with a constituent whose little granddaughter died after leaving special care because she was discharged and, a few days later, became ill and there was a policy not to readmit a neonate to special care once they had gone home to the community. Have you had any feedback from your members on whether there is a pressure to discharge babies perhaps before they are ready because of the pressures on the

service? Secondly, have you heard of any other cases like that? It seems to me that a neonatal outreach team would have been ideal in that situation, because she was admitted to a general paediatric ward where she was exposed to levels of infection that she would not have been exposed to had she been on a neonatal ward. A neonatal outreach team would have been really beneficial in that sort of situation.

[169] **Ms Boyd:** I am thinking of the members we spoke to at our conference last year. I think that it is a common practice that, once you have left neonatal care, you do not come back, because of the risk that you could bring infection back into the unit, which could spread and cause major infection or even death for the babies in that unit. However, going on to a general paediatric ward has its dangers. You need a good outreach service to act as a bridge for that gap. I am thinking of members we spoke to in England who said that you can live in an area that has fantastic resources but 10 miles down the road there is nothing. If you have a good outreach service you may prevent readmission, but, if admission is needed, unfortunately, they go to a general paediatric ward. I do not know how you would get around that, because of the risk of infection being brought into the neonatal unit.

[170] **Lynne Neagle:** It is tricky.

[171] **Ms Boyd:** Infection on neonatal units has been in the press a great deal lately in various areas. It is a very scary issue.

[172] **Eluned Parrott:** I understand that there is some evidence demonstrating the importance of parental contact, with regard not only to bonding but the clinical outcomes for many special care babies. What support are units able to provide to allow that mother-baby contact where the mother is also ill? I have been made aware of circumstances where the mother has been told that she is too ill to go to the special care baby unit and that the baby is too ill to come to them and they have spent two whole days apart before they have been reintroduced after the birth.

[173] **Ms Boyd:** That is a problem that we see, because you cannot transport a vulnerable sick baby down two floors to another unit or across to another side of the hospital. I do not know how you can get around that if the mother is too ill to visit and the baby is too ill to go to her. You would have to carry out a risk assessment and it would depend on the individual case.

[174] **Dr Richardson:** It is just as Pam has outlined. You have a conundrum in that situation. One approach is to facilitate the father's involvement; very often, the father being able to bring back information is fundamentally important in the mother maintaining a level of contact.

[175] **Ms Boyd:** I do not know whether it is still operating, but some years ago some units had closed-circuit television above each cot space that the mother could access from her bedside. I do not know whether that is still in some units. I did not know of any in Wales at the time, but some units piloted that system.

[176] **Christine Chapman:** We could ask that question.

[177] **Ms Boyd:** There are issues of funding, privacy and so on.

[178] **Jocelyn Davies:** I would be watching mine all the time if that were me.

[179] **Ms Boyd:** That is something that you could use in a difficult situation. If you only had one camera, you could move that baby into that space and that mother into the corresponding space—although you would have every mother saying that they wanted to go

there.

[180] **Jocelyn Davies:** I can see the attraction.

[181] **Suzy Davies:** The inappropriate use of cots is something that we have heard about from Bliss and something that you have highlighted in your paper. You have spoken about it a bit already. Do you agree with the findings of the neonatal network capacity review that different distribution of neonatal capacity may be required between units? In other words, are the cots in the wrong places at the moment?

[182] **Ms Turnbull:** Our position is that the real problem is that there are not enough cots.

[183] **Suzy Davies:** Everything is undercapacity.

[184] **Ms Turnbull:** Our general position would not be that we have sufficient cots and that they are simply in the wrong place; our general position would be that there are not sufficient numbers of cots.

[185] **Suzy Davies:** May I press you a bit further on level 1 in that case? Is there undercapacity there?

[186] **Ms Turnbull:** I would have to come back to you on that specific question. I am happy to do that.

[187] **Suzy Davies:** Okay, thank you.

[188] **Jocelyn Davies:** I would be quite interested in a note on the different qualifications that you were describing earlier, how you get there and perhaps the costs and time involved in someone doing those qualifications. I would find that very informative.

[189] **Christine Chapman:** Yes, would you be able to do that?

[190] **Dr Richardson:** I would be able to provide that, Chair.

[191] **Christine Chapman:** That will be very helpful.

[192] **Mark Drakeford:** I have a question about transport and transfer. There is now a neonatal transport service in Wales, and your evidence is positive about the development. You go on to suggest that it ought to run 24 hours a day rather than 12 hours a day. I would like to get a sense from you of whether a long list is developing of more things that need to be done. Where does this fit in with your sense of priorities? In all of the things that we are hearing about where more needs to be done, where does a move from 12 to 24 hours sit? Is it a ‘must-do’, a ‘good-to-do’ or a ‘nice-to-do’? When choices come to be made, I want to know where this is on your list.

[193] **Dr Richardson:** I am sure that Pam will have a view on this. I am sure that it must be seen as a ‘good-to-do’. The introduction of the service as it stands now is a really significant step forward. Given the constraints on financial resources, the provision of cots and nurses is perhaps the most important area, alongside the medical expertise provided. I would say that it would be a good thing to do.

[194] **Ms Boyd:** I would also say that it would be good to do. Looking at the evidence, it is not about, statistically, how many transfers occur outside that 8 a.m. to 8 p.m. slot. However, based on clinical experience, the ones that you are transferring after 8 p.m. tend to be the sickest and the most vulnerable. It would be good to have a dedicated team, from a nursing

point of view, that would take your baby safely to the correct unit, and it would be good for the parents to know that someone is coming who has specialist skills rather than their being told, 'You are fifth on the list but there's been an RTA', or 'Someone's had a heart attack so you've been moved down the list so your baby can't go yet'. That is a strain on a family that is already under a lot of pressure, so I think it would be a good thing to do.

[195] **Mark Drakeford:** That is very helpful.

[196] **Eluned Parrott:** I want to ask a bit more about support for parents. This question is to you, Pamela. In your evidence, you talk about support for parents varying from one unit to the next and you provide a list of things that a unit should ideally have, such as parent accommodation, counselling services, quiet places for parents and so on. The Minister for Health and Social Services has reported that all local health boards are either fully or partially compliant with the all-Wales neonatal standard. First, is there a difference between that standard and what you see as the ideal as you have outlined it? Secondly, what other action would you like to see to improve the standards across the health boards?

11.00 a.m.

[197] **Ms Boyd:** We are moving in the right direction. There is accommodation. In an ideal world, when you have a new build, then you should have accommodation for every parent who wishes to stay close to their baby, and a quiet area where parents can go to be spoken to for updates, and perhaps for news that is not what they want to hear. There should also be an area where they can sit and liaise with other parents as informal support, and areas for siblings. We are constrained by money, and we are constrained by space, so this would be in an ideal world, but we should have counselling services for parents—perhaps not just for the parents who lose their babies, but also for those whose babies have a life-limiting, ongoing disease that will mean that they will go into paediatric services. That would bridge the gap between the neonatal services and the paediatric nursing services. There should be areas where parents can have meals, so that they can bring in a take-away and eat it in the kitchen of the ward. I am talking ideally, but if we are to provide the best service for families through a traumatic time, that is what I would like to see. From speaking to our members, I know that we have all said, 'If only we had another bedroom, or a sitting room, or an area where they could go and perhaps take the babies who, although not well, are not critically ill'—there should be a quiet space for them, rather than always being on the ward where there is noise, and other parents.

[198] **Eluned Parrott:** Absolutely. Looking at counselling, which is obviously a critical issue for parents at a time of appalling stress, it has been my experience that it is generally delivered not by a specialist counselling service, but by midwives or neonatal nurses themselves. What do you think are the potential benefits and drawbacks of having a dedicated counselling service for the bereaved, and for families who have children with difficulties?

[199] **Ms Boyd:** There should be such a service. Speaking from the association's point of view, if you have a specified counsellor with those skills, who can help a family through a very difficult time, I think that each unit should have access to that kind of counselling. You can talk a parent through the time of death of a baby, and outreach nurses may go out and see that family on an ad hoc basis—perhaps it is not part of their role, but they feel that they should go to make sure that somebody is there for them—then they are lost in the community, and three or four months down the line they still have all these issues. There is no designated area where they could go that is neonatal-specific.

[200] **Eluned Parrott:** When a baby is born, the health visitor visits, and one of the things that they monitor is issues such as postnatal depression in the mother and the health of the mother over a period of time. Are you suggesting that that service is not provided to the same

extent to mothers whose baby has died?

[201] **Ms Boyd:** I think that it is provided, but the feedback from outreach nurses that I have come into contact with over the years is that the parents think that, because you are from the neonatal unit, you understand more than the health visitor might, or the midwives—because you may have known that baby on the unit, and you may have popped in to see that baby and known that family. They can then have that continuity, so they often feel that they can open up to you rather than somebody that they have just seen through their GP, or met at an antenatal clinic. Neonatal nursing tends to take a holistic approach, rather than the attitude that, once you have gone through the door, you are not ours anymore. You remain a neonatal family.

[202] **Eluned Parrott:** Would it not therefore be beneficial to provide counselling training to neonatal nurses and midwives, rather than perhaps having a step-removed counselling service that was not able to offer the depth of information medically about what had happened in this specific instance?

[203] **Ms Boyd:** There might be a lot of neonatal nurses who would want to go on to do counselling training. I think that it depends whether they want to extend their role and come away from the neonatal service. You want to be able to give parents time. You do not want to have to look at that as your whole role. It is not just a drop-in service. You can be with a family for quite a long time and, as neonatal nurses, maybe we ought to have more counselling skills so that we help parents through, and help ourselves and our colleagues through stressful times.

[204] **Christine Chapman:** I would like to ask the Royal College of Nursing's representatives about the generic training for nurses that you just touched upon, Pamela. Is counselling included in the early training of nurses? Obviously, it is a separate role as well. I know, for example, that there is more emphasis on that now with medical students, but I do not know about the nursing side.

[205] **Dr Richardson:** It is now an initial and essential component of all forms of nursing midwife preparation that new practitioners should have the high-level communication skills that are required to offer a counselling service that is helpful to people. It is important to stress that this is very significant when a family loses a baby, but also when a family has a baby who has a long-term changed-ability health status, because that really does constitute bereavement for a family as well. The demand for this kind of skill is quite high. Again, it is a patchy picture: some units have placed priority on ensuring that the skill mix is present, but others less so. Back to provision of education, we need specific education for the existing workforce and a skill mix that has the knowledge and skills that families need.

[206] **Keith Davies:** Mae Cymdeithas Meddygaeth Amenedigol Prydain wedi pennu safonau nyrsio. Yn y sefyllfa bresennol, lle mae prinder arian, pa mor realistig ydyw i'r byrddau iechyd gyrraedd y safonau hynny?

**Keith Davies:** The British Association of Perinatal Medicine has set nursing standards. In the current situation, where there is lack of funding, how realistic is it for the health boards to meet those standards?

[207] **Ms Turnbull:** Investment will be required to keep up to the standards, but one thing that we have always argued is that you have to look at measuring the cost of not providing the investment. We have already spoken about readmissions and how to handle that issue. As well as the tremendous emotional, social and health cost of vulnerable babies being ill or needing readmission, there is also a financial cost to the system as a whole. Therefore, one thing that we have always been clear about as the Royal College of Nursing—and this is across all areas, not just neonatal nursing—is that there is clear evidence of the relationship

between the number of staff provided and, crucially, the education and qualification level—the skill mix—of the staff provided and the health outcome. That is true in all areas. Therefore, the point that we would make is that you do require investment. In any organisation, staffing costs are the majority of your costs, but there is so rarely such an obvious relationship between the money that you are spending and the outcome you are getting. That is what we are saying needs to put back in, going back to the statutory point about performance. That is how the organisation, ultimately, needs to be judged. If it is a health provider, it should be judged on the quality of the health outcomes. That is the response that we would make. There is a cost, but there is also a cost to not doing it.

[208] **Christine Chapman:** I have one final question. We have discussed various aspects for this inquiry. Can you give me a sense of what would be your main priority? Can you give us one main recommendation? We will obviously take everything on board, but is there one priority that is pressing for you? Is there one recommendation that the committee should be aware of?

[209] **Ms Turnbull:** It would be to address the staffing situation. In order to do that, there are things that you need to address in education as well, but if I had to choose one, it would be staffing, because in order to meet that recommendation you would need to deal with the education issues.

[210] **Dr Richardson:** I would amplify that. It is important that there is commitment to establishing a well-prepared workforce that is adequate to the needs of neonatal patients and their families in Wales.

[211] **Ms Boyd:** I agree. We should aim for neonatal nurses to be qualified in the speciality, and then you will have a quality workforce.

[212] **Christine Chapman:** Thank you for that. I thank you on behalf of the committee members for attending today; it has been a very good session. We shall consider the evidence. We will send you a transcript of the meeting, so that you can check the record for accuracy. Thank you again for attending today.

[213] Before I close the meeting, I would just remind Members that the inquiry will continue this afternoon. If we can, I would like us to start back here at 12.45 p.m., when we will be taking further evidence from other witnesses. That brings this morning's meeting to a close.

*Daeth y cyfarfod i ben am 11.10 a.m.*
*The meeting ended at 11.10 a.m.*