



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

**Y Pwyllgor Iechyd, Lles a Llywodraeth Leol
The Health, Wellbeing and Local Government
Committee**

**Dydd Mercher, 25 Tachwedd 2009
Wednesday, 25 November 2009**

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Inquiry into Wheelchair Services

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

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Lorraine Barrett	Llafur Labour
Peter Black	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats
Andrew R.T. Davies	Ceidwadwyr Cymreig Welsh Conservatives
Irene James	Llafur Labour
Ann Jones	Llafur Labour
Helen Mary Jones	Plaid Cymru The Party of Wales
David Lloyd	Plaid Cymru The Party of Wales
Val Lloyd	Llafur Labour
Darren Millar	Ceidwadwyr Cymreig (Cadeirydd y Pwyllgor) Welsh Conservatives (Committee Chair)

Eraill yn bresennol
Others in attendance

Keith Bowen	Cyswllt Teulu Cymru Contact a Family Wales
Michael Butterfield	Unigolyn Individual
Joanne Davies	Unigolyn Individual
Peter Hosking	Swyddog Polisi, Swyddfa y Comisiynydd Plant Cymru Policy Officer, Office of the Children's Commissioner for Wales
Nicki Shercliff	Unigolyn Individual

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

Claire Morris	Clerc Clerk
Sarita Marshall	Dirprwy Glerc Deputy Clerk

Dechreuodd y cyfarfod am 9.16 a.m.
The meeting began at 9.16 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

[1] **Darren Millar:** I welcome Members and any members of the public who may be joining us in the gallery. I remind people that headsets for simultaneous translation and amplification are available. If anyone has any problems using them, the ushers will be able to help. Committee members and members of the public may wish to note that the translation

feed is available on channel 1, while channel 0 broadcasts the language being spoken. I would be grateful if everyone could ensure that all mobile phones, pagers and BlackBerrys are switched off so that they do not interfere with the broadcasting or other equipment. If it is necessary to evacuate the room or the public gallery in the event of an emergency, everyone should follow the instructions of the ushers, who will be able to guide you to the appropriate exit. Finally, I remind Members and witnesses that the microphones are operated remotely, so you do not need to press any buttons. I have not been notified of any apologies or substitutions, other than the fact that Helen Mary Jones will be joining us a little later. I invite Members to make any necessary declarations of interest under Standing Order No. 31.6. I see that there are none.

9.17 a.m.

**Ymchwiliad i Wasanaethau Cadeiriau Olwyn: Tystiolaeth gan Swyddfa
Comisiynydd Plant Cymru
Inquiry into Wheelchair Services: Evidence from the Office of the Children's
Commissioner for Wales**

[2] **Darren Millar:** Item 2 on our agenda today is a continuation of our inquiry into wheelchair services. We will be taking evidence from the Office of the Children's Commissioner for Wales. I am pleased to welcome Peter Hosking, the policy adviser, to our committee this morning. Welcome, Peter. We appreciate the paper that you sent, which has been circulated to members of the committee. We have had a chance to look at it and I think that we have indicated that we would like to go straight to questions, if that is okay.

[3] Will you tell the committee what prompted the involvement of the office of the children's commissioner in highlighting problems with wheelchair services in Wales?

[4] **Mr Hosking:** The Office of the Children's Commissioner for Wales runs an advice and support line that children and young people, and people who are supporting children and young people, can call with any concerns. Normally, that line will signpost them to other people who can help, but there comes a time, occasionally, when there is no-one out there who can help and the office of the children's commissioner feels the need to intervene. We have had about eight calls about wheelchairs in the last few years. One of the more recent ones highlighted serious concerns in mid Wales, which I have detailed in my paper. Although it was one call to the office, the caller represented a group of people and all their views were put forward.

[5] **Darren Millar:** Eight calls seems to be a relatively small number.

[6] **Mr Hosking:** Yes, it is. The number of calls to our office is not huge anyway. We get something like 500 or 600 calls a year and, of those, eight about wheelchairs is not too small a number.

[7] **Peter Black:** Peter, you mentioned in your paper that you received a list of concerns from a parent in Powys about the services received at the artificial limb and appliance centres. Could you briefly outline the main problems experienced by those families in relation to the provision of wheelchairs?

[8] **Mr Hosking:** The main problem is the waiting times. Most people would agree that when they get a service, it is reasonably good, but the waiting times to get a wheelchair in the first place, and occasionally to get repairs and adjustments made, are far too long. It can be 15 to 18 months from asking for a wheelchair to getting one, in which time the child grows and the child's condition may also change. So, sometimes, by the time the wheelchair arrives, it is

already not fit for use, because of the development of the child.

9.20 a.m.

[9] **Peter Black:** Do you know whether the parents, before contacting you, had been in touch with the artificial limb and appliance centre?

[10] **Mr Hosking:** Yes, they had been in touch with ALAC over many years. They said that, in the past, communication with parents was not very good, but that that has improved very much over the last few years.

[11] **Peter Black:** You have touched on my follow-up question there. Is there a clear line of communication whereby parents can take up grievances and get feedback?

[12] **Mr Hosking:** I am not sure about that. We were considering carrying out a review and, had we performed a review, that would have been one of the things that we would have considered. However, we were informed that a review was already under way, commissioned, I believe, in May 2008, and it would have been irresponsible for us to duplicate that effort. To date, we still have not seen the results of that review, and I am not sure whether it has been made public, unless it has very recently.

[13] **Darren Millar:** I think that we were told that the review has still not been completed.

[14] **Andrew R.T. Davies:** I can understand why you did not commission your own review. In answering a question of mine earlier this week, the Minister for Health and Social Services said that stage 1 of that review is now complete, and that it is sitting on her desk awaiting appraisal, and, hopefully, after that appraisal, the results will be made available. In hindsight, do you regret that you did not commission a review, given the length of time that has now elapsed in getting to the end of stage 1 and not even getting to stage 2? We are talking about some 18 months now. You will be aware of the big issues that are out there; this review was supposed to give some sort of cohesion and strategic direction to improving the services across Wales. So, with hindsight, would it have been appropriate for you to commission your own report?

[15] **Mr Hosking:** We first made inquiries about this in November of last year, and we were told that a review was already under way. We were also told at that time that the review was expected to be completed by March. So, had that happened, there would be no need for hindsight and we would have been happy to wait that long. So, yes, in hindsight, we could have embarked upon a review, but it would have been such duplication of effort and public funding.

[16] **Andrew R.T. Davies:** However, you would probably have come out with your findings a bit sooner, which could have complemented the work of the Welsh Assembly Government.

[17] **Mr Hosking:** Indeed.

[18] **Andrew R.T. Davies:** We have heard about the waiting times and about the problems that people have encountered in accessing the more complicated wheelchairs, particularly electric wheelchairs. In your paper, you kindly provide us with a breakdown of the information that you have received from the ALAC centres in Cardiff and Wrexham. What impact do long waiting times and not having access to this type of service have on the ability of families to adapt and to try to get the best out of life? You have an all-Wales remit, so you can comment on this from across Wales, rather than just regionally.

[19] **Mr Hosking:** I will put a scenario to you in response to your question. If a child could not go out of the house because they did not have a pair of shoes to enable them to do so, families would do something about that very quickly, no matter what it took. However, when it comes to the provision of wheelchairs, so that children can get around and be mobile, families are at the mercy of the agencies that provide them, and that has a significant effect. To continue my analogy, if a child did not have a proper pair of shoes, they would not develop properly and their development would be seriously stunted, because they were unable to engage in all of the things that children should be able to engage in. Play is a prime example in this, because children who are wheelchair users and who have no mobility are unable to play and socialise with their peers. That is a fundamental right under the United Nations convention.

[20] **Andrew R.T. Davies:** We understand the delays—or have been told about them. Your paper complements the information that the committee has gleaned so far. What particular factors are the primary obstacles in bringing the waiting times down? Is it as simple as saying that there are three key factors in the debate that could be solved if they were addressed, which would result in waiting times being diminished?

[21] **Mr Hosking:** Since I wrote the evidence, I have continued to look into this, and have called a paediatric occupational therapist to ask about the service in the area where the parents who contacted us came from. I am told that, up until about three or four years ago, the local occupational therapist was able to organise a clinic at a children's centre, and that five or six children would go to the clinic and would all be seen on one day. I am told that now—I think that this still happens at the Cardiff ALAC, but I suggest that you get the evidence directly from occupational therapists—at the Wrexham ALAC, the technicians will drive for possibly two or three hours to get to some parts of their area; they see one child but do not see another child who might be in the same school at the same time, because that child is not next on the waiting list. That is what I am told, but I suggest that you ask occupational therapists. What would improve services is if occupational therapists were more able to organise things at a local level. Families sometimes have to travel huge distances in order to get seen. I know that the service goes out to schools as well, but it is a huge problem for families, and for families with disabled children, it is, obviously, even more of a problem than it would be for other families. So, there are issues such as that.

[22] When speaking to the occupational therapist, I was told that the therapist made a referral for a powered wheelchair. She described the child to me as having the greatest need that she had ever seen for a powered wheelchair. That case was referred to the ALAC, but its management team turned down her request for a powered wheelchair because the child had been assessed as needing a manual wheelchair. We are not talking about Joe Bloggs off the street saying, 'This child should have one'; it is a professional opinion, but it seems not to have much effect at the ALAC.

[23] **Andrew R.T. Davies:** Your understanding is that that issue is greater at the Wrexham centre than at the Cardiff centre.

[24] **Mr Hosking:** That is what I am told, yes. I do not know about powered wheelchairs in the Cardiff centre, to be honest; that only came up in relation to the Wrexham centre. I am told that there are differences, and I noticed in the Record of Proceedings the other week that the Minister was talking about substantial time differences between the north and the south—I think that she mentioned a wait of 15 months in the north and 5 months in the south. I am not sure what the situation is with regard to powered wheelchairs at the Cardiff centre, but I am referring to a referral to the Wrexham centre.

[25] **Darren Millar:** You have given an example of a non-effective use of resources. If someone visits someone at their home, should they not be able to visit someone else in the

area, who may have been waiting a week? At least that would get it done and there is no time wasted on travelling. Is that the only problem in north Wales? According to your evidence, in south Wales, people who use the Cardiff ALAC are waiting up to 161 days just for an assessment if they are in need of a complex chair. It is clear from the evidence that we have received that it is the waiting for the assessment that appears to be the longest part of the process. Is it a staff resourcing issue? Is it the fact that they need more local clinics? What is the problem? From the information that you have gathered, why is it taking such a long time?

9.30 a.m.

[26] **Mr Hosking:** As I said, we have not conducted the review yet, so we cannot answer those questions in detail, but it seems to be the strict reliance on waiting lists rather than seeing as many children as possible that is causing the problem.

[27] **Darren Millar:** You are essentially saying that it is on a first come, first served basis.

[28] **Mr Hosking:** Yes, I think so. You would need to check with the centres on this, but, as I understand it, it seems that technicians will travel a long distance to see one child and not see another child in the same area. I cannot see how that is the most efficient way of doing things, but I do not know what service and financial framework targets have been set. If the targets are set so that they have to adhere to waiting lists, they will obviously have to do that.

[29] **Darren Millar:** There are the national service framework targets, which are out of the window as far as this is concerned.

[30] **Mr Hosking:** It is six weeks for assessment and eight weeks for delivery. It is nowhere near those targets. If the NSF targets are so unrealistic, I wonder why they were put in; they might have been put in without consultation.

[31] **Darren Millar:** Are those targets so unrealistic? What is your assessment of them? We are aware that some parts of England are managing to achieve an 18 week turnaround, which is slightly longer than the targets, but at least people are being assessed and have their equipment in that amount of time.

[32] **Mr Hosking:** If we could keep to the targets in the NSF, that would be excellent. I do not think that anyone could expect a better service than having a wheelchair in 14 weeks. Parents are realistic about this; they know that it is difficult, but it seems to be far more difficult than it needs to be.

[33] **Lorraine Barrett:** Do you think that the wheelchair services are effective at meeting the needs of each individual child and young person, particularly those with complex needs and those needing powered wheelchairs? Once they get the service, is the service able to—

[34] **Mr Hosking:** I am not sure whether ALACs provide that service. I am told that most parents who feel the need to go for a powered wheelchair get it through voluntary organisations such as Whizz-Kidz, and they do that themselves. There does not seem to be a lot of joined-up working between the voluntary organisations and the ALACs. Most of the onus to get alternative wheelchair provision seems to be placed on the parents and it goes through charity funding. It does not seem right that they have to do this. Parents with children in wheelchairs already have quite enough to do, without having to make their own referrals and so on. We were contacted many years ago, when I first started working with the children's commissioner, by Whizz-Kidz, asking whether there was anything that we could do to influence better working with wheelchair services in Wales and we made some representations on that. That was a long time ago, and things have improved since then.

[35] **Lorraine Barrett:** You have talked about those on the waiting list. Do you have any knowledge of how cases might be prioritised and whether they are being effectively prioritised, as opposed to being on a first come, first served basis?

[36] **Mr Hosking:** I do not have information as to how they are prioritised, but from what I have been told, it would appear that there is a strict adherence to the waiting list, rather than prioritisation.

[37] **Lorraine Barrett:** Rather than need.

[38] **Mr Hosking:** Yes.

[39] **Lorraine Barrett:** We have received information from parents in Powys, and it is mentioned that part of their concern is that, when the chair is issued, how that chair might be used in different situations is not always taken into account. An important question is how a chair can be used in the school toilet. Can you expand on those sorts of situations?

[40] **Mr Hosking:** Not in great detail. However, I would also say that children have all sorts of needs. For example, they have a right and a need to engage in play, sport and leisure, and, with appropriate wheelchairs, children can play football and do all of the things that most other children can do. However, getting those kinds of things provided is almost impossible. It seems that we are looking at a very medical model of what a wheelchair is, whereas a wheelchair is a pair of legs to the rest of us, and we use them for all sorts of social, educational, and developmental things. So, I think that we need to get away from the medical model and to look at the child's needs in the round.

[41] **Lorraine Barrett:** I probably know what the answer to this question will be from the answers that you have already given, but do you think that there is sufficient assessment, or do you think that there is room for improvement in assessing children's needs as a whole, as you said, and not just the medical need?

[42] **Mr Hosking:** I think that there is significant room for improvement.

[43] **Helen Mary Jones:** My apologies for being a little bit late this morning. In the experience of the office of the children's commissioner, are users who need to be reassessed or whose wheelchairs need updating or improving adequately served by the current service?

[44] **Mr Hosking:** No. We asked the centres what the timescales for regular reassessments of equipment were, and we were told that there were not any regular reassessments. Before you arrived, I mentioned that I had been speaking to an occupational therapist, and she said that when a wheelchair arrives she is tempted to make an immediate referral, because by the time you get that referral it will be about the right time to reassess the wheelchair. That cannot be a very good way to run a service, can it?

[45] **Helen Mary Jones:** Indeed not. How effective, in your view—again, you may or may not be able to answer this, depending on the information that the commissioner's office has—is the service in meeting the needs of a range of service users? In terms of language, for example, do you know whether it is able to assess through the medium of Welsh? Is it able to respond to people from different ethnic minority communities, who may have different cultural needs in terms of the way an assessment is done? Also, in relation to geographical location, we have had some evidence that suggests that there is quite a big variation in how effective the service is, depending on where you live.

[46] **Mr Hosking:** I do not have any information about Welsh-medium provision. As I was saying, we have been considering doing a review, but we have not actually done one, and

that would be one of the things that we would want to ask about if we were to do so. There does seem to be a big black hole somewhere in Powys; that is all that we know. It is a black hole, and it is funny, because this particular area receives services from both Wrexham and from Cardiff. Apparently, there have always been fluctuations, in that some of the services were better and some were worse. However, we are told that in the last three or four years the service from Wrexham has become considerably worse, and the service from Cardiff is considerably better—something like three times better—according to the figures that the Minister mentioned the other week, of 15 months and five months respectively.

[47] **Darren Millar:** In the evidence that we received last week, we were told that the further you move away from the Wrexham epicentre, effectively, the worse the services seem to be for those people in need of wheelchairs. For example, north-west Wales was also being very poorly served by the centre. Do you have any information on that?

[48] **Mr Hosking:** No, but if you have long travelling times and arrive somewhere and only see one child, that would explain why the service was bad in the places most distant from the centre, would it not? We are told that, in the past, when the local occupational therapists organised clinics, they came and saw five or six children, and the service was much better then.

[49] **David Lloyd:** Peter, you have touched on several of these issues, but I will ask the questions anyway for the record. In your view, how effective are the current arrangements for commissioning and providing wheelchairs through the regional ALAS centres?

9.40 a.m.

[50] **Mr Hosking:** I would say not very effective, particularly considering the developmental needs of children. Children's needs are more acute; I am not suggesting that the needs of adults are not acute, but when you consider the developmental needs of children, then their needs are particularly acute.

[51] **David Lloyd:** Moving on, how should wheelchair services be organised to improve services within the new local health boards?

[52] **Mr Hosking:** We need to look at giving more of a professional input to local paediatric occupational therapists, and I suppose the same could be said in relation to adult occupational therapists. I gave an example earlier where their referrals are not necessarily taken as a referral from a co-professional. They may not be able to do the technical assessment or the measurement of a wheelchair, but surely they can help to prioritise which children need the wheelchair most.

[53] **David Lloyd:** We have heard mention of the Welsh Government's current review of wheelchair services. What would you like to see included in that review?

[54] **Mr Hosking:** It needs to look at waiting times in particular, although when I first made inquiries about it, it rather sounded as if one way of making waiting times fair would be to make them equally bad everywhere. So, I am not sure, but it is about looking at working smarter. It is not necessarily a matter of more resources; it is about using those resources more effectively.

[55] **David Lloyd:** On the back of that, what discussions have you had with the Welsh Government regarding this wheelchair review?

[56] **Mr Hosking:** Not many. We have been awaiting the review so that we have some facts to discuss. We have been told, again and again, that it will be out soon.

[57] **Darren Millar:** Was the office of the children's commissioner not invited to give evidence to the review?

[58] **Mr Hosking:** No.

[59] **Darren Millar:** Not at all?

[60] **Mr Hosking:** No.

[61] **Darren Millar:** In spite of the information that you had already had furnished to you? Did you voluntarily pass some of that information on?

[62] **Mr Hosking:** We spoke to the civil servants who were conducting the review, and they said it would be done soon.

[63] **Darren Millar:** But you were not formally invited to give evidence?

[64] **Mr Hosking:** No.

[65] **Darren Millar:** I find that astonishing. Andrew, did you have a comment?

[66] **Andrew R.T. Davies:** You stole my thunder to an extent, Darren. I was going to ask Mr Hosking what input the office had into the review. I find it almost shocking that the office of the children's commissioner has not submitted evidence formally to the review.

[67] **Mr Hosking:** Do not forget that it was commissioned in May of last year, so by the time we asked—

[68] **Andrew R.T. Davies:** It should not have necessarily been you asking, though. You should have been approached as an interested party. It calls into question the confidence that you can have in such a review. Would you agree with that?

[69] **Mr Hosking:** Well, yes. Obviously, there are capacity issues anyway. It depends what kind of a review was being conducted. If it was just a review that was based on paper evidence and waiting lists from the various offices—I was told that it was particularly looking at waiting lists—then we would not necessarily have the information about waiting lists to contribute. However, it is always nice to be asked to contribute to reviews.

[70] **Darren Millar:** You do have information about the impact on the lives of children, of course, do you not?

[71] **Mr Hosking:** Absolutely, yes.

[72] **Darren Millar:** You have cited some cases in the paper that you sent to us, including the particular case in Powys, which, quite frankly, are appalling.

[73] **Ann Jones:** Are the rights of disabled children and young people in Wales, such as the rights under article 23 of the United Nations Convention on the Rights of the Child, being met by the current wheelchair services?

[74] **Mr Hosking:** It depends where you live, and that should not happen.

[75] **Ann Jones:** So unless you live in Wrexham and Cardiff, the answer is probably 'no'.

[76] **Mr Hosking:** Absolutely. Many disabled children live in rural areas, and I would say that those particular children's needs are not necessarily being met, particularly when you consider that there is less public transport and so on.

[77] **Ann Jones:** You articulated in your evidence some of the issues that affect young people and how we perceive wheelchairs. You referred to the fact that a wheelchair is a person's legs, and that children in wheelchairs should be able to have the same quality of life as any other child. Do you have any more evidence on how quality of life is compromised when disabled young people face these long delays?

[78] **Mr Hosking:** I think that there was a report by Contact a Family on wheelchairs in schools, and some children—because they did not have the right wheelchair, or possibly because they did not have the right desk—are unable to sit at a desk like their peers. One young person—who was eight years old and a very brave young lady—contacted us because she was in a wheelchair and her school asked her to arrive half an hour after the other pupils and to leave half an hour early, so that she would be safe and so that the wheelchair would not block the corridors. That is just one rather extreme example, and actually the child's parents were quite happy with this arrangement—parents of disabled children tend to be very protective. However, we contacted the school and pointed out that she was not getting her full right to education, and it immediately changed things. It is just that people had not really considered the situation properly.

[79] **Ann Jones:** There is an issue here about educating people. The school—we will give it the benefit of the doubt—was trying to protect that child and to ensure that there were no health and safety issues. There is an educational issue here about people understanding what they are doing. They may think that they are doing things for the right reasons, but the segregation, of course, is—

[80] **Mr Hosking:** Yes. We had another case where there was a young person in a wheelchair who needed to be moved occasionally at school, and, because of manual handling and health and safety regulations, the teachers did not feel that they were able to do this. So, the parents had to come in, simply to move their child to a more comfortable position. If you can imagine not sitting in an appropriate wheelchair with the appropriate support, you are going to get more tired than other children. If you cannot transfer from the wheelchair to the toilet you are probably not going to drink as much water as other children, which will have an effect on your health and your ability to concentrate.

[81] **Irene James:** In your paper you refer to the protocols and standards in the children's national service framework. In your experience are the protocols and standards effective, and should targets be used to further meet the specific needs of disabled children and young people?

[82] **Mr Hosking:** The targets that are in the framework are good ones. If they were met, then there would be far fewer problems with wheelchair provision. It was very disappointing when we first saw the NSF that of all the targets for disabled children, so few of them were flagged for early delivery. We are now four or five years on, and some of the targets for wheelchair provision have still not been met. As far as I know, without doing a review, there is no single referral process for ALAS and the rehabilitation engineers. That means that, for example, ALAS will provide a chair, but, as I understand it, the rehabilitation engineers then have to do the mouldings for the seat and it does not seem to be a joined-up service. I can understand why these specialist centres were needed, because it is a very specialist provision, and it would have been ridiculous to split this off into 22 local health boards. However we might consider, now that we have seven local health boards, whether each one could make a better provision.

[83] **Darren Millar:** The Wrexham ALAC serves predominantly north Wales—and, I appreciate, parts of Powys as well—but the LHB would not serve a significantly different geographic area to that which is currently being served from Wrexham, would it? Does that therefore mean that the service will still be as bad in north Wales and that it might need two or three centres?

9.50 a.m.

[84] **Mr Hosking:** I am not able to answer that question. I do not have sufficient knowledge to know how that would work out.

[85] **Darren Millar:** I understand that you do not have a view on that.

[86] **Mr Hosking:** It might be worth looking at. It would not be worse, presumably.

[87] **Darren Millar:** No, but—

[88] **Mr Hosking:** Do you know what I mean? I spoke earlier about giving more power to occupational therapists, not ‘power’ exactly, but more of a say in what happens with the provision of wheelchairs and in arranging clinics and so on. If they were all part of a local health board, I presume that that would be easier; however, I am not entirely sure about that.

[89] **Andrew R.T. Davies:** It does not seem to be rocket science. From the evidence that you have given, it just seems to be a centralised control-and-command model, with the occupational therapists not being able to manage their own caseloads. I was surprised to hear that they go to schools and are told that they can only see one pupil, for example, when they may well know that there is a second pupil or even a third at that school who needs to be seen. When you think that the Wrexham centre’s coverage stretches all the way to Aberystwyth and then up to Anglesey, to send someone out to do just one visit is illogical. The centre may well think that it is logical because it might not understand the complexities of the area. Would it be fair to say that there is no devolution of control, if you like, to the professionals on the ground so that they can manage their caseloads? In some respect, perversely, you are actually creating a rationing system.

[90] **Mr Hosking:** Absolutely. I would describe it as gate keeping.

[91] **Andrew R.T. Davies:** Or rationing.

[92] **Mr Hosking:** Honestly, without doing a review and looking into these details, we really could not say, but it does seem to be that they have worked smarter in the past.

[93] **Andrew R.T. Davies:** Would it be fair to say that all gate keeping equals rationing?

[94] **Mr Hosking:** I suppose that it would. It is rationing the service in one way or another, is it not?

[95] **Darren Millar:** Do you think that the rationing comes down to resource issues, not just in terms of human resources and the need for specialists in the field, but financial resources? Have you had any information or evidence on that?

[96] **Mr Hosking:** We have been told that, in the past, it has worked better, and I am not sure that they had more resources in the past than they have now—it is extremely unlikely, is it not? Obviously, if we wanted to bring the waiting lists down to meet the NSF targets, that probably would require more resources. However, if we wanted to improve the service, it may well be improved significantly by working smarter.

[97] **Irene James:** From what you are saying, it sounds quite simple to just work smarter, but did it always work better for everyone? If you are seeing two or three children in a school where you were originally seeing one, somebody else's child, in another school, is being left behind.

[98] **Mr Hosking:** That is true, but for one six-hour car journey, you are seeing three children rather than one. So, in that sense, it has to be an improvement, does it not?

[99] **Irene James:** I just asked that question to play the devil's advocate because it does not always seem smarter if it is your child who has been left behind.

[100] **Mr Hosking:** Absolutely. However, do we want our highly skilled technicians spending their time driving or do we want them spending their time providing services to children? I would suggest the second.

[101] **Darren Millar:** I think that that brings us to the end of these questions, unless there is something that you wanted to add, Peter.

[102] **Mr Hosking:** No, that is fine. Thank you for the opportunity to contribute this morning.

[103] **Darren Millar:** Thank you for coming along and giving us the opportunity to question you on the evidence that you have provided. We appreciated the paper and we will ensure that you get a copy of the transcript of today's meeting. If you have any further information for us, please do not hesitate to send it on. Thank you.

[104] **Mr Hosking:** Thank you very much.

9.54 a.m.

Ymchwiliad i Wasanaethau Cadeiriau Olwyn Inquiry into Wheelchair Services

[105] **Darren Millar:** We will move straight into item 3 on our agenda and continue with our inquiry into wheelchair services. I am pleased to welcome Michael Butterfield, Joanne Davies and Nicki Shercliff. Both Michael and Joanne are parents of wheelchair users, and Nicki is a wheelchair user. We are delighted to have you here today and we appreciate the opportunity to hear your stories. It is also an opportunity for you to speak on behalf of those who would love to be sat with the committee, giving evidence. We have received some notes from you, Joanne, which were circulated to Members this morning, so not everyone will have had the opportunity to read those notes. Given that we have only just received these notes, it might be helpful if you could just give us a little of your story before we move on to the questions. I do not know who wants to start. Joanne, do you want to speak to the paper that you provided?

[106] **Ms Davies:** I have been trying to tackle that for some three years. The service is getting worse. It is appalling. That is why I am here today. I am a carer and I have taken time out to come here to address you all because I feel that the Artificial Limb and Appliance Centre, as a service provider, is accountable to no-one, but it is about time that it was. We are dealing with some of the most vulnerable people in society and it does not seem to be accountable to anyone, nor does it prioritise any emergencies that arise that need to be addressed. It seems to be above everything, and it is about time that it took notice of the parents, the paediatric consultants, the orthopaedic surgeons—those who have the expertise. It is time that the centre stood up and took notice. That is why I am here today.

[107] **Darren Millar:** Thank you. That is why we are conducting this inquiry. We are as concerned as you are about the service. Michael, would you like to add anything?

[108] **Mr Butterfield:** I am Michael Butterfield from Llangattock. I am a father of three. My eldest child, Morgan, has cerebral palsy. He will be eight next April, but he is more like a 13-year-old the way that he bosses us about. I am here to give a parent's perspective and to speak on Morgan's behalf. Not only that, as Jo said, those working in the system are fighting the same battle. We have had to go privately for both manual and electric chairs. I will go into further detail on this with you this morning.

[109] **Ms Shercliff:** I have used this service for both manual and electric wheelchairs. My view is that those working in the service do not listen to the users of the service in terms of getting anything fixed or in relation to equipment.

[110] **Darren Millar:** So, you refer to repairs and your equipment upfront. Is that right?

[111] **Ms Shercliff:** Yes.

[112] **Darren Millar:** I should have said that Keith Bowen is here as well today. Thank you for the evidence that you provided last week, Keith. We appreciate that you are here to give support to the witnesses today.

[113] I want to ask a general question that relates to the way in which you access the service. It seems that it is inconsistent for different people around the country. When you made your first application for a wheelchair, how easy was it to access the service the first time around? What information and support was there to guide you through the process, if any?

[114] **Mr Butterfield:** In my experience, in Powys, there is a north/south divide. In south Powys, we were lucky at the start—bearing in mind that this was four and a half years ago. We had to wait three months; I smile as I say that because people in the north of the county have to wait a lot longer. Our initial experience was of a manual wheelchair. On our last holiday, in 2005, the manual wheelchair came out to Spain with us and fell apart. That ruined our holiday. When we came back, we purchased a £2,600 manual wheelchair ourselves. There is a problem with regard to confidence in the service.

10.00 a.m.

[115] However, later down the line, we had to look at getting an electric wheelchair. As parents, we have a duty of care towards our child to ensure that they proceed down the pavement towards the home in safety; however, the fact is that when Morgan goes off the kerb, the wheelchair rattles back and forth. My attitude to that is to return the wheelchair and to source our own. We then went to the Caudwell Children trust, and, within six weeks, it provided us with £7,000-worth of funding. We funded the additional £1,700 ourselves, and now we have an electric wheelchair, on which we cover the maintenance costs.

[116] This year, we took Morgan and our two other children to Legoland for his birthday, and, Morgan being Morgan—and as a result of us trying to get him to be more independent—he decides to bunny-hop off a kerb outside Windsor castle. *[Laughter.]* It was Good Friday, so what could we do? We got to Legoland, eight elastic bands later, which repaired the wheelchair for the time being, and then the charger goes. So, when we got back, we contacted the wheelchair provider, which, in fairness, came to sort the problem and we were faced with an £800 bill, which we covered. We phoned the Artificial Limb and Appliance Centre—or the Artificial Limb and Appliance Service as it now likes to be called—and we were told that we

were on our own. The service covers the cost for our tyres to be changed every nine months—which I had to fight Keith Roberts from ALAS for—and that is it. I passed that information on to the occupational therapists in Powys, so that they could pass it on to the parents of children with the same needs. However, Keith Roberts then gets on the phone to occupational therapists in Powys and says, ‘How dare you pass on that information?’. So, this is the situation that we have. Naturally, as parents, we are fighting a totally inadequate system. We share information and, suddenly, ALAS is onto the occupational therapists telling them not to share that information because it will open the floodgates.

[117] **Ms Davies:** ALAS is very territorial about its information. Consider the fact that it takes three months in the south of Powys, while I had to wait 18 months for a chair. The usual system of referral involves a chair being issued through your OT. So, I initially had a buggy for John. There used to be a clinic every so often at which they would see many children, and it worked very successfully. To be frank, it is now all to do with their waiting lists. They are adhering to waiting lists rather than to the children’s needs. I received a chair in 2004, which had to last three years, and you must bear in mind that there is no review system in between. If you put a child in the same shoes for three years, you would be had up for neglect because a child grows. That is three years in which you have no back-up whatsoever. You have access to Serco, which is the company that helps to repair the chair if it starts falling apart, but Serco will only adhere to certain criteria. If there are things on that chair that it feels that it cannot address, it will put it to ALAC as an emergency, but ALAC may never address those issues.

[118] By January, I will have waited three years for the next chair. In the meantime, I had a chair that was too small. Okay, my child was bowled over in the chair by a younger child, which does happen in the playground, but it happened because he was too big for that chair. The chair got tipped, he had a stroke-like episode and he was rushed to Hereford County Hospital. That is why I am here today and why I have taken it to Peter Hosking and Keith Towler—I want you all to realise that this is a children’s rights issue. I have underlined articles in the United Nations Convention on the Rights of the Child that, as a Government, you should be looking at, because the basic needs of these children are not being met. A wheelchair for a child or for anyone who cannot get around is a prerequisite, and that is all there is to it. Last week, I had an argument with ALAC because the zip on my son’s harness had broken, and I was told, ‘We will be with you in a week, Mrs Davies’. I said in response that the situation was rendered as an emergency and that if he lunges out of the chair, which he does, he will pull the chair on top of himself. That would render him housebound and redundant from school for a whole week. So, I spoke to Alison Ravenscroft, who is the chief executive of ALAC, and I had to battle with her to get that repaired. She has come around now that she has listened to me, but she has listened because I am here today.

[119] **Darren Millar:** There are a few issues that we need to pick up on there, and I invite Members to come in at any point, because, while we have some areas that we want to cover, it is important that we deal with issues as they arise.

[120] First, Mike, you mentioned the issue of having to fund wheelchairs yourself, because of the unacceptable delays in accessing them through the service, and then having to cough up for the maintenance of those wheelchairs thereafter. Is that because you had purchased them privately, or would that have been the case had the service provided exactly the same wheelchair to you?

[121] **Mr Butterfield:** You are treated like a purple sheep—because you have gone private, that is it. The service cannot adapt to the fact that you have gone private—you are either in the ALAS club or you are not.

[122] **Darren Millar:** But you went private because you were not getting a decent service, because the waiting times were unacceptable.

[123] **Mr Butterfield:** Forgetting the service for a moment, the product that was delivered was not fit for purpose, and that raises a wider issue. I come here with many hats on: as a parent, as a representative of the health professionals who look after my child, and as a taxpayer. The question that you have to ask is this: when an electric wheelchair is funded, what is the value to the taxpayer? The chairs that are allocated at the moment are not fit for purpose. If you look at what we have and at what is provided by ALAS, you can see a huge difference, a chasm. As with anything in Wales, we are not after a gold standard service; we are after at least a basic level of service. What is provided falls far short of that.

[124] **Ms Davies:** May I pick up on that point? You talk about taxpayers, but surely, ALAS is responsible to the taxpayer because, if you have to wait 18 months for a chair, it will be too small by the time it arrives, making it redundant. Surely, it is wasting money. We have a Labour Government, yet people are going private for motorised wheelchairs. This is the point: we have a Labour Government and people are opting out of the system.

[125] **Darren Millar:** We have a Labour-Plaid Cymru Government here in Wales.

[126] **Ms Davies:** Well, whatever—it is a socialist Government.

[127] **Darren Millar:** The point is that you felt unable to wait such a long time for a wheelchair, and, not only that, you could not rely on the quality of the wheelchair when one would arrive, having seen what happened to the wheelchair that fell apart when you went on your holidays.

[128] **Mr Butterfield:** For many parents, their problem is with the length of the wait, but, for us, it was with the quality of the wheelchair.

[129] **Darren Millar:** After the disaster that you suffered on your holidays.

[130] **Mr Butterfield:** Yes. When my child is 18, I do not want to look back and say, ‘I wish we had done this or that’, because that would be failure. To me, in a country of some 3 million or so, it just does not seem right that we have a service divided into two. You are chucking money—and you will keep on doing that—at a service that will, quite honestly, just sap the cash. The way forward is to look at an all-Wales service rather than a divided one. Maybe we need radical change.

[131] **Darren Millar:** That is an interesting point.

[132] **Ann Jones:** I want to tease something out. You talk about the quality of the product that ALAS would have provided. Do you think that it does not listen to the views of people such as yourself when you tell it that there is a chair on the market that would better suit your child’s needs and so your child would get more use out of it than what ALAS provides? You have called what ALAS provides a substandard service, because of the provider it uses. Do you also think that it is happy for you to fund your child’s chair yourself as that takes the onus off the body, as well as the maintenance costs, because, having gone private, you are not part of the system? The cynic in me thinks that that is probably how it looks at this. Is there anything that we can do, such as to ask why, if a product such as the chair that you now have is on the market, that cannot be included in the procurement of ALAS?

10.10 a.m.

[133] **Ms Davies:** With regard to chairs, I have been to the Naidex conference—the big disability conference held in Birmingham—and I have identified certain chairs that I thought were appropriate for my son, but ultimately it comes down to money and what the providers

think is suitable. They will say, 'Well, this is the chair that we have in our system, and it is suitable', and you have to go with that. You either go with what they feel is right, or you opt out of the system. I am now thinking of getting a motorised wheelchair and a mobility car, but this is where it all snowballs, because until I have the specific type of chair that I want, I cannot apply for a mobility car because I would need to know the type, the make and the height of the chair and so on. So, it delays that. I have to have an assessment for a motorised wheelchair, which my OT has told me that very few children in the north of the county are getting, and the assessment that they have to undertake is an adult assessment. So none of them pass, so no-one has had a motorised wheelchair.

[134] **Mr Butterfield:** It is a service that is in absolute disarray.

[135] **Darren Millar:** I think that Nicki wanted to add something here.

[136] **Ms Shercliff:** Going back to the wheelchairs that the service provides, I cannot afford to buy my own wheelchair, so I have to go with what I am provided with. Although some of the chairs have been good, at the moment I cannot use my powered chair because it is too uncomfortable for me to sit in. I have not been assessed; my measurements were taken and I was given that chair.

[137] **Darren Millar:** So you have been provided with a chair for which you have not been assessed; the service has just gone out and spent money on procuring that chair on your behalf.

[138] **Ms Shercliff:** Yes.

[139] **Darren Millar:** That is incredible. You were making the same point, Michael, about chairs not meeting individuals' needs, but still being provided because the service can afford to pay for them, rather than for the right wheelchair.

[140] **Mr Butterfield:** I am faced with the prospect, in the next year, of having to go out to get a new chair. I will go private yet again, because that is the situation that we face. Naturally, you try your best for your child. I go to bed every day asking, 'Have I done my child justice?' I ask you to go to bed tonight and ask yourselves whether you have done justice today. We are in a situation where we will have to go private again. I will still try to work with ALAS and ask whether it cover the maintenance costs at the very least. However, the door is closed.

[141] **Darren Millar:** Yes, because you have gone private. Andrew R.T. Davies wanted to come in at this point.

[142] **Andrew R.T. Davies:** Thank you for your evidence; it is among the most powerful evidence that I have heard over the last two and a half years, since I have been at the Assembly, because it comes straight from the people who the lack of service affects. I am grateful to you for the way in which you have presented your evidence today.

[143] There are a few points that I would like to pick up on. In the evidence session earlier, just before you came in, I raised the issue of the rationing of the service. From what all of you have said, whether it is the assessment, being able to get the equipment that you require, or just getting an understanding, it seems that every obstacle possible is put in your way. Would it be fair to say that your assumption is that the service is almost rationed in Wales, and that the resource is spread so thinly that users are not getting the service to which they are entitled? 'Entitled' is the right word here.

[144] **Ms Davies:** It has been three years since Johnny, my son, has had a clinic for a new

chair. He has scoliosis of the spine and wears leg splints. Someone is coming out to see him tomorrow, because I have created holy hell, which is hard for a parent to do, because you do not want to always be the enemy, but, frankly, you are. That person is coming out tomorrow, but I will still not see an OT—I have not seen an OT for possibly three years. My son's posture is paramount. I will tell you about the way things are set up in the north—I do not know how it works in the south.

[145] Someone came out last Friday. He was very rude, because he had had to travel two hours to bring a new harness. I said to him, 'Please make sure that the harness is big enough, because you have not seen him in 18 months, and he has grown significantly'. He came with a harness that he thought was appropriate, but it was too small. Thank goodness, he had brought another harness, but it was, really, also too small. The man could not fit the harness on the chair, because he had not brought a drill with him. He had travelled two hours, and he had been most rude because he had had to come out. My husband fitted the harness. I said to the man, 'I will need you to come out again, because he is having a new brace next week, and the harness will be rendered redundant again'. He is coming out tomorrow, and I am still not being provided with an occupational therapist. I asked him whether he was a qualified occupational therapist, and he said, 'No, I can do the measurements—that is enough'.

[146] **Darren Millar:** That brings us on to the whole area of assessments. Peter wants to explore some issues about waiting for assessments.

[147] **Peter Black:** You have outlined how the delays and problems with the provision of wheelchairs affect your daily lives. Are adequate interim solutions provided while you are waiting for the assessment and delivery of wheelchairs?

[148] **Ms Davies:** There is nothing, is there?

[149] **Mr Butterfield:** I cannot answer, because we have opted out of the system. We are fighting for many things for our children, not just only for Morgan with cerebral palsy. We have opted out, because why waste time in the system? We have gone private, and our assessments are private. Our only involvement with ALAS is from a maintenance point of view. When bills come in, they are paid out of the family kitty. We have not gone on holiday for four years. It chips away, and it affects my other two children.

[150] **Darren Millar:** If someone is waiting for their first wheelchair after having an assessment, does ALAS provide anything at all in terms of support?

[151] **Ms Davies:** I would just like to mention a scenario here. I was speaking to my occupational therapist the other day, because I said that I was coming here, and this issue came up. There is a child in Powys who has very complex needs, and has been waiting for an assessment for a specialised pushchair, which is the first thing that you go for. The orthopaedic surgeons, the OT and the paediatric consultant have written to ALAS to say that this child is at risk because the child needs a suitable harness and chair. I do not know who is on the ALAS board, but whoever they are, they obviously have expertise beyond everyone else, because they have said, 'No, that child cannot be seen as a priority'. What gives the board the authority to do that? It has clear evidence that that child is at risk, and it still deems the child not to be a priority. There is no review process. I do not know whether that is your experience, Nicki, that it provides something in the middle. I have never had such an experience with ALAS.

[152] **Ms Shercliff:** ALAS did not come. I had to go to it or the Rehabilitation Engineering Service to get it to come round when I feel that it is appropriate. It does not come to check how I am getting on with the chair—I have to phone to say, 'Right, it is time for you to do something about this'.

[153] **Darren Millar:** That is dreadful.

[154] **Peter Black:** That is obviously a far from satisfactory situation, but what is the situation like in relation to contacting ALAS? Does it have an easily accessible complaints procedure? Can you lodge a complaint or get through to the appropriate person quickly? What is the communications interface with it like?

[155] **Ms Davies:** We are parents dealing with big issues every day, and this is one little issue in our lives. Having to lodge complaints, and having to come done here today, takes a lot. You can get through to ALAS—it has got better—but people will say that they will ring you back and they never do.

[156] **Peter Black:** So, you can get through, but the response is inadequate?

10.20 a.m.

[157] **Mr Butterfield:** I will provide evidence to the clerk that you can photocopy and take away and provide to the committee, of occupational therapists lodging complaints on behalf of clients and themselves and a lack of response coming back from ALAS, and, when the response eventually comes back, it is skirting around the issue. I will happily provide that evidence.

[158] **Ms Shercliff:** My experience is that, when I try to get hold of someone, because I live independently now, they do not listen to me, so I always have to put my carer on the phone. My carer has to fight my corner when I can fight it myself.

[159] **Darren Millar:** I will ask about the reassessment process. Joanne mentioned earlier that you had not seen an OT for three years. How regularly do you think there should be a reassessment? Obviously it will vary from case to case, and from individual to individual, but what is the longest period someone should go without having a review from an OT?

[160] **Ms Davies:** Six months at the most. Some children have more complex needs than others, but you would not expect them to wait for a pair of shoes any longer than that. This is a prerequisite; they have to be seated suitably. I have already talked about 18 months from time of measurement to time of delivery, and when it comes it is redundant. What is going on there?

[161] **Darren Millar:** Nicky, you say that the motorised chair that you have been provided with is uncomfortable and is not really meeting your needs. Is that a situation that is being addressed?

[162] **Ms Shercliff:** We have tried to address it with my OT and we have an engineering team. Anything we do still does not help. If I send it back, I am left without a chair that gives me my independence.

[163] **Helen Mary Jones:** Joanne, you mentioned that it is driven by waiting lists rather than the needs of an individual child. Will you say a bit more about that, and how you think that affects the way in which it delivers the service? Other people have said similar things to us.

[164] **Ms Davies:** In the past, when I first was referred to ALAC—I do not know if its whole structure has changed; it probably has—you would be referred by your OT, you would have a clinic every six to nine months, where a bunch of us would go to be assessed. The OT would know who was on the list, and then, in six months, we could have a review. The

reviews do not happen now. Once you have had the chair, that is it. It is not a system that is ongoing; you have to be re-referred. These are people who are never going to go back out of the system. They are re-referred, so you go back to the back of the waiting list. I am twenty-second on the waiting list at the moment, and I have been waiting nearly 16 months for a review, as I would call it. The only reason they are coming is because I have created a stink and not a lot of parents want to do that; that is the reality. It is just appalling.

[165] **Helen Mary Jones:** So, you think that it is driven by ticking the boxes on the list, rather than by clinical—

[166] **Ms Davies:** Llandrindod Wells is two and a half hours from Wrexham. They will come and see that named child. If that named child is twenty-first on the waiting list, they will come to see that child; they will have a look at what needs to be done and they will go. Another child might be in the same classroom and it might not be a big issue—this is common sense to me—and they will go away and that child will have to wait another so many weeks until he or she is seen. You tell me, but it is waiting lists as far as I am concerned.

[167] **Helen Mary Jones:** There is no logic to it, is there?

[168] **Mr Butterfield:** This is just an observation, but a lot of things in life are a matter of common sense. To me, we are here for the long term. You can chuck money at this now and provide some quick short-term wins, but, fundamentally, the system itself needs a whole review. You can chuck money at it and it will just fall into a black hole. Am I right in saying that Health Commission Wales contracts ALAS? That is the structure, is it not?

[169] **Mr Bowen:** That is about to change.

[170] **Darren Millar:** Yes. We are exploring that in a future meeting.

[171] **Mr Butterfield:** It begs the question: as well as holding ALAS to account, should you also include Health Commission Wales? It contracted ALAS, so is it reviewing the level of service that ALAS provides? This comes back to the issue of providing value to the taxpayer.

[172] **Darren Millar:** That brings us neatly on to the area that we wanted to explore. Val, your question is next.

[173] **Val Lloyd:** As service users, how would you like to see wheelchair services organised and what improvements would you like to see carried out?

[174] **Ms Davies:** First, I would like it to be accountable to someone. During the last few years, as a service user, I can tell you that it is appalling. If it was anyone else, it would be accountable and there would be an overhaul. I understand that you have had meetings on this before. I have had sight of meetings, but I would like to see a radical change. As I said, I would like to see reviews undertaken every six months so that, with a child's or an adult's changing needs, it is looking, in the long term, for suitable chairs and equipment. These chairs are not cheap, but if they are no good to the user, you are wasting taxpayers' money.

[175] **Val Lloyd:** More importantly, they are not meeting the needs of the user.

[176] **Ms Davies:** The point is that at the moment, people are going to charities and are getting a better service from Whizz-Kidz and such charities—

[177] **Mr Butterfield:** There is also the Caudwell Children. I want to go on record in mentioning Caudwell Children.

[178] **Ms Davies:** They are going to charities. If it said to me tomorrow, 'You cannot have a motorised wheelchair', I would go to a charity; that would be my next stop. I know that it is private, but I would have to try to get funding from different places. I would get a better service from them than I would ever get from ALAS at the moment.

[179] **Mr Butterfield:** There is a note from Ellis Peters, an occupational therapist in Brecon, which states that ALAC does not appear to want to co-operate with private fundraisers and wheelchair charities. That is our experience. We have a situation where money is tight in Wales and in Great Britain. Do we have a service that is part-funded by the charities? If, at the end of this, we get an all-singing, all-dancing service, so be it. This is all about working together to deliver a service that is fit for the end user.

[180] **Darren Millar:** I think that Nicki wants to come in.

[181] **Ms Shercliff:** We want something that is simple to navigate around and not have all of these different services doing different things. We want one simple place that you can go to and where you know that you will get all of the services that you need.

[182] **Darren Millar:** I will bring Andrew in in a second, but some of the evidence that we have received indicates that, essentially, in order to address the accountability issue that Joanne raised, it would be good to split the one service up to correspond with the new LHB areas, so that those services could become accountable to the local health boards in terms of what they provided in each area. Obviously, that would then mean having eight ALAS-type services across Wales. However, you also talk about consistency and the need for a single service. How can those two things be reconciled or can they be reconciled?

[183] **Ms Davies:** I cannot answer that, because I do not have the expertise to say what sort of system—

[184] **Mr Butterfield:** I do not think that it comes down to expertise—it is a matter of common sense. This is a small country and having eight different services costs a lot more than would one service. Surely to have one service and to get things right within that one service would lead to the provision of a better and more consistent service than having eight separate services within Wales.

10.30 a.m.

[185] **Val Lloyd:** What prompted that question was previous evidence by individuals and organisations that the service varies the further you live from the centre in Wrexham or from the centre in Cardiff.

[186] **Ms Davies:** There is a big inequity between the north and south. We had a meeting in Brecon not so long ago, which the head of the service in the south attended. The service is not great in the south, but it is far better in the south than it is in the north at the moment. I do not know why, but it is. In the past, it has been the other way around. I do not know why that is, but it seems to be the case at the moment.

[187] **Mr Butterfield:** Sorry to backtrack, but this is an important point: we need wheelchairs to meet the needs of the user. A classic case is Morgan's. He has the same rights as any other child and should be given the same opportunities. Obviously, there are varying sizes of tables in his school, but we want him to be at the same level as his peer group so that he can communicate with it. So, we want a chair that goes up and down, and that is what he has got. I do not know whether it has changed, but the current situation is that Health Commission Wales's and ALAS's stance is that that is not a priority need. I am sorry, but it

is, because the end user asks for that.

[188] **Ms Davies:** I read a case study from Contact a Family Wales, where they wanted a chair that could go back and in which the child could be independent. It said that it could not meet both criteria and could only meet one criterion. There is another example where the wheels on the chair were inappropriate, which meant that they could not access the outside—the child could not live an engaging life. It said that that did not matter because it was meeting the child's clinical needs, and that that was enough.

[189] **Andrew R.T. Davies:** What bothers me greatly in the points that you have raised is this accountability point. Frankly, accountability leads to service improvement, because you take account of the observations that people make. This is a public service, at the end of the day, but the evidence that you have provided clearly demonstrates that the service seems to be completely above everything and that it does not have to pay attention to anyone.

[190] Joanne said that she had read about previous meetings and she is right, because a review into wheelchair services was undertaken around 18 months ago and is ongoing. Do you think that accountability of the service has deteriorated recently or has that deterioration been evident during all of the time that you have been users, given that you have used the service over quite a considerable period of time, or has it got steadily worse over recent months?

[191] **Ms Davies:** The deterioration has been there, from my experience. Johnny is now 10 and when I first got his pushchair back in 2002, the service was working for me. I cannot answer the question on accountability—I did not hold it accountable for anything because everything was working. Since I had the wheelchair in 2004, it is highly dismissive if you challenge its OTs. I have only ever seen two OTs from ALAC, but if you challenge them—unfortunately, it may not be their fault, but they are on the ground level and your frustration will be channelled at someone—ALAC says that it cannot help the situation because its computer systems are down and so on. As a parent, you have to deal with that daily and you do not want to know about the computer system. The important point is that it is not accountable to anyone. It is arrogant of the service to go over the heads of orthopaedic surgeons, who say that the child is at risk because they cannot have a suitably adapted chair, and to get its clinical team to say, 'Actually, we will not deem this a priority'.

[192] **Andrew R.T. Davies:** In your paper, you identify one point—I think that Michael also raised this—when you try to complement the service by buying private kit or by working with a charity, because you cannot get the necessary service from ALAC. You are pushed even further to one side. Has that also speeded up over time? Is the fact that you have tried to complement that service via the private or charitable sectors a new philosophy, or do you feel that that has always been the ideology in the service?

[193] **Mr Butterfield:** I should imagine that my name is dirt in ALAS, because—

[194] **Andrew R.T. Davies:** I just want a general feel.

[195] **Ms Davies:** Unfortunately, ALAS has brought this on itself. I do not believe in going privately because I think that it is elitist, and many people in society cannot afford to. I am going privately only because I hope that I can get funding from a charity, so I am not saying that I can afford it. The one chair that I have looked at costs £20,000 because it allows the user to go from a seated to a standing position. They have fantastic pieces of equipment in Naidex but the majority of us cannot even begin to access those sorts of equipment because their prices are beyond us. If ALAS will not provide it, it pushes us into a corner. Our children are our main focus and that is what has driven us to come here today. We have to look at what is right for them, and if that means that we have to go privately, we will. It has

provoked that response from us by telling us, 'You are not suitable for a motorised wheelchair'. Only two OTs have seen my child since he was 10 years old. What right does ALAS have to make a judgment about whether he is suitable for a certain piece of equipment?

[196] **Andrew R.T. Davies:** The crux of my question is on personal choice and respect for the needs of the individual. The picture that you have painted of the service is one of there being almost no such thing as an individual, and that you must have whatever the service dictates you will have.

[197] **Mr Butterfield:** Totally.

[198] **Darren Millar:** Nicki, do you want to add to that?

[199] **Ms Shercliff:** You do not get a choice. Years ago, I tried to get the wheelchair that I wanted from my ALAC, but because it was not a standard one, they would not fund it.

[200] **Darren Millar:** Even though it suited your needs better.

[201] **Ms Shercliff:** Yes.

[202] **Darren Millar:** You are probably aware that there is also a Welsh Assembly Government review under way into wheelchair services. As part of that, has any contact been made with you, as service users at the sharp end, or at the coal face of receiving those services? Have any of you been contacted, or are you aware of other service users who may have been contacted as part of that review?

[203] **Mr Butterfield:** I have certainly not been contacted. I do not know whether it falls under that, but I know that ALAS sent a therapist—and I felt for that lady because she was really thrown into the lions' den that day—and a complaints manager to south Powys. Joanne was there, too. My attitude is that when a service is that grave, you should send the top dog so that he or she can see exactly what is happening at the grass roots, and can keep in touch. There was talk earlier in the year of setting up a steering group, and a gentleman called McKenzie was meant to chair it. I said that that was fine, and asked whether there would be any end-user representation on that group, but I was told that there would not be. I told them that I would like to be involved, because otherwise they would not get any feedback from the grass roots, but I have not heard anything since. I have chased it up, but I got nowhere. So, whether that is continuing without any input from an end user, I do not know.

[204] **Ms Davies:** I am here today only because I contacted the commissioner's office in Swansea to say that this situation is contravening children's rights, or the rights of the most vulnerable people in our society. I said that ALAS was not addressing their needs and I asked them to do something about it. I have liaised with Peter Hosking and I have written two e-mails to Keith Towler about it. That is why I am here today.

[205] **Darren Millar:** Nicki, do you want to add anything?

[206] **Ms Shercliff:** No.

[207] **Darren Millar:** Do Members have any further questions for the witnesses?

10.40 a.m.

[208] **Val Lloyd:** I want to ask whether there are any further issues that the witnesses would like to raise.

[209] **Ms Shercliff:** I was given funding for an occupational therapist from Equinox until recently and, through the OT, I was able to get some training on how to use my power chair, but I was not able to get used to moving around in the outside environment.

[210] **Darren Millar:** We have not really touched on training for the users of the chairs that are provided. You obviously did not get adequate training, Nicki.

[211] **Ms Shercliff:** No. Equinox provided my training, but since my OT left, that has fallen by the wayside. I have never had an OT provided for me, apart from ringing the LHB to ask it to do that kind of stuff. It has helped with getting the equipment, but not with the rehab.

[212] **Darren Millar:** So, you think that it is important to have consistency by being allocated the same OT, using the same equipment and getting the training and the rehab afterwards.

[213] **Ms Shercliff:** Yes.

[214] **Darren Millar:** Thank you for that point. It is very important. Do the witnesses want to raise any other issues? I see that you do not. In that case, if there are no further questions, we will bring the session to a close. Thank you for your evidence. It has been extremely powerful and will contribute to our report and our recommendations. I will ensure that you have the opportunity to look at it once it is completed. Thank you for taking the time out of your schedules to be with us today.

[215] That brings us to the end of our meeting. I remind Members that our next evidence-taking session on wheelchair services will be on Wednesday, 2 December.

*Daeth y cyfarfod i ben am 10.43 a.m.
The meeting ended at 10.43 a.m.*