

**COMMUNITY DEVELOPMENT AND JUSTICE  
STANDING COMMITTEE**

**INQUIRY INTO ACCOMMODATION AND INTENSIVE FAMILY  
SUPPORT FUNDING FOR PEOPLE WITH DISABILITIES**

**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
WEDNESDAY, 19 MARCH 2014**

**SESSION ONE**

**Members**

**Ms M.M. Quirk (Chair)  
Mr I.M. Britza (Deputy Chair)  
Mr C.D. Hatton  
Mr M.P. Murray  
Dr A.D. Buti**

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**Hearing commenced at 9.36 am.**

**Mrs LEE-ANNE BRENSSELL,  
Chief Executive Officer, Headwest, examined:**

**The CHAIR:** On behalf of the Community Development and Justice Standing Committee, I thank you for your interest and appearance before us today. The purpose of this hearing is to assist the committee in gathering evidence for our inquiry into accommodation and intensive family support funding for people with disabilities.

You have been provided with a copy of the committee's specific terms of reference. The committee is one of the Legislative Assembly of the Parliament of Western Australia. This hearing is a formal procedure of the Parliament and therefore commands the same respect given to proceedings in the house itself. Even though the committee is not asking witnesses to provide evidence on oath or affirmation, it is important that you understand that any deliberate misleading of the committee may be regarded as a contempt of Parliament. This is a public hearing and Hansard will be making a transcript of the proceedings for the public record. If you refer to any document during your evidence, it would assist Hansard if you could provide the full title for the record.

Before we proceed to questions today, I need to ask you a series of questions. Have you completed the "Details of Witness" form?

**Mrs Brensell:** Yes.

**The CHAIR:** Do you understand the notes at the bottom of the form about giving evidence to a parliamentary committee?

**Mrs Brensell:** Yes.

**The CHAIR:** Did you receive and read an information for witnesses briefing statement provided with the "Details of Witness" form today?

**Mrs Brensell:** Yes.

**The CHAIR:** Do have any questions about being a witness at today's hearing.

**Mrs Brensell:** No.

**The CHAIR:** You have made a submission to the inquiry and together with the information you provide today your submission will part of the evidence to the inquiry and may be made public. Would you like to make any amendments to your submission?

**Mrs Brensell:** No.

**The CHAIR:** Would you like to make an opening statement?

**Mrs Brensell:** Certainly, if I can. I had anticipated that today you would have before you some of our families and people who are going through the CAP process. Unfortunately, I was unsuccessful in securing anyone to talk to you and I am concerned about their reasons for not doing so; that is, they are fearful of what it might mean for their place or position in the process. For us and the people who we support, they not only have experiences across sectors and multiple services, but also they play in the space of disability compensation and insurance and they also play in the aged care federal system. Whether or not it is appropriate, for them having something is extremely vital. They also know what is out there and they do not want to jeopardise getting something that could potentially benefit their lives and/or the people they are caring for. We have produced anecdotal evidence in our submission. We collected much more evidence, but people were just not keen to

have that referenced nor were they keen to speak and provide evidence. That is an indictment on the system that we are asking them to participate in and apply to. I am quite concerned about that. I am not sure that I did not know that before, but it is very sad when people tell you that they really do not want to talk because they fear jeopardising their CAP application.

[9.40 am]

**The CHAIR:** The inquiry is a short one and the report will be out in May. You might want to go back to some of those people because we have the capacity to have a hearing in private and, obviously, we would not refer to people by name in our report. That option is available. I mention that now so that if people would like to give evidence in those circumstances, we can accommodate them.

**Mrs Brensell:** I definitely spoke to some of our families about that. One of their concerns generally is that if they are going down the pathway of compensation, generally there is an understanding they will not be eligible for CAP because all of their avenues have not been exhausted, yet we know that on average that process takes between six to eight years to come to fruition, let alone the people who are 100 per cent deemed at fault. Those people generally have nothing; however, if there is any inkling that they can re-enter or there may be a review of their case, there are definitely tensions there and they are not prepared to jeopardise what they think might be a small gain for a process that they might not get anything out of. They regularly hear from the commission, their local area coordinators and people they are involved with that this is the last resort. If you have not tried everything and you are not able to prove that, there is no point applying for CAP.

**The CHAIR:** In your submission you mention that providing evidence of a disability is a significant barrier to obtaining CAP for those who have acquired brain injury. Can you expand on that further?

**Mrs Brensell:** The eligibility criteria of being eligible and/or registered with the commission would take a separate inquiry of its own, but it is definitely a barrier for people with an ABI. Not only will people generally not recognise themselves as having a disability, but getting evidence and proof of that disability is expensive and takes time. There is also a barrier in the current system because the Department of Health neurosciences unit does not like to provide neuropsych assessment or proof of eligibility for the commission. It is a bit of a catch 22. You need the evidence to prove the disability, yet the only stream of access that people generally have is the private system, which is expensive. I am talking anywhere from \$2 000 to \$6 000 for a neuropsych assessment. It is a barrier.

**The CHAIR:** Is the public system willing to do that because it is seen as outside of delivering a medical service?

**Mrs Brensell:** And it is difficult to be specific about what it is that will benefit that individual. What my organisation and team tends to do is to work constructively around why it is we need to know the specifics about a person's brain injury and what it means to them. It is not just about registration or eligibility for the commission; rather, it is about a range of accessibility issues and about a range of issues that they may have barriers to, all of which contribute to a good life. We talk about what it might mean potentially for them as a barrier to employment, as a barrier to maintaining connectedness with their family, and barriers to a range of other things, and that is why we need to know their level of disability. We then use it to gain registration and eligibility for commission support. Our group of people are predominantly people with brain injury and they are underrepresented in the disability sector, yet they are overrepresented in our prisons, our homeless population and our health sector—and definitely in the aged care sector from a federal point of view.

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**Dr A.D. BUTI:** You mentioned aged care. I note that a lot of younger people with acquired brain injury enter aged care facilities.

**Mrs Brensell:** Definitely. The number of younger people under the age of 50—or say 65, but even under the age of 50—is still quite high nationally purely because there is nowhere for them to go. There is no suitable accommodation to meet their care needs and no funding support to provide the level of care they need. Generally, there are no opportunities for them to return home.

**Dr A.D. BUTI:** Do you have any numbers?

**Mrs Brensell:** I think nationally it is definitely over 600. In Western Australia it could be between 80 to 100.

**The CHAIR:** I think Brightwater said it was 80. A few years ago there was a COAG initiative to get young people with ABI out of nursing homes. Has the funding dried up?

**Mrs Brensell:** It did. It was a federal initiative that started in 2005 and ended in 2011. There was a state government commitment at the last election of \$9 million. The only evidence I have seen of any commitment moving towards allocating and spending that has been a \$6 million commitment, but nothing has really happened and that was in the last budget. We have not heard anything about that and we are not sure where it has gone. Predominantly that should be for younger people who are inappropriately institutionalised in a nursing home. But we are not sure who will facilitate it, who will have input into it and what it will look like for younger people.

**Mr I.M. BRITZA:** This is a sensitive question, and an ignorant one. I gather there are different stages of ABI. We have been talking about youth with ABI being placed in aged care centres. My natural thinking is that if the ABI is serious, they would not know. I understand it naturally, but can you tell me the problem of putting younger people with ABI into aged care?

**Mrs Brensell:** The obvious problem is that a nursing home is for end stages of life—it is where you go potentially when you need to die. For younger people, regardless of whether or not they are severely disabled, the medical model in Australia is particularly very good at keeping people alive and getting them back out of the hospital system and into the community. Admittedly, what their disability and their level of disability looks like is undetermined, but regardless they are human beings who have families and connections and they have a right to have experiences like everyone else their age. The other issue is that their level of rehabilitation and their level of care needs are generally not met. People will be left without the appropriate level of physio, occupational therapy or the early interventions that they need in the rehabilitation phase or in the first two years potentially post trauma. The staff at aged care facilities do not have the ability or the skills to best support them and provide the caring and nurturing environment that younger people need.

There are increasing issues about people's relationships and connections and their interpersonal relationships and how that needs to look for younger people when families, in particular, come to visit and how that looks when there is a husband and a wife scenario. There are a range of issues that younger people in an aged-care setting present that create issues for not only the individual, but also the staff and the organisation.

**The CHAIR:** I remember someone telling me once that it was something as fundamental as having the young patient wheeled into some activity that they had in the home and having a heavy metal music fan and having to sit there and listen to renditions of the Andrew Sisters or something. It is fundamental stuff like that.

**Mrs Brensell:** Definitely. It is about maintaining connectedness. Say, for example, it is a 40-something-year-old male who has a wife and two children. That is not only not a grand environment for young kids to be hanging out in, but also it is not an acceptable environment for that younger person to have intimate moments with his wife, nor is it conducive to him having his friends over for a barbecue, to have a beer or to do all those things that a 40-something-year-old person might

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naturally be doing. I do not think that disability or a brain injury excludes people from having a good life, or at least having an opportunity to experience those things.

[9.50 am]

**Mr I.M. BRITZA:** I was thinking of serious brain injury and —

**Mrs Brensell:** I think behavioural issues is probably one of the other areas that we might want to talk about and what that may look like for a younger person if they have a lack of insight and they are short tempered, they lack empathy, they are unable to communicate effectively and they get frustrated and then lash out. A chemical restraint may be used in response, which we say is not appropriate, but we would probably find that there is high use of that on younger people in nursing homes purely because it is easier to manage people if they are quiet and they conform.

**Mr C.D. HATTON:** I refer to the access to accommodation for ABI people. Is there difficulty getting into that accommodation quite often and can those organisations decline to take them?

**Mrs Brensell:** Definitely. There is a definite gap and an access issue for people 18 years and under. A person between the ages of 16 and 18 generally has nowhere to go. They cannot attend a Brightwater facility because they are under 18. They are working towards potentially having a facility where they can take those younger people of 16 to 18. I want to point out that the prevalence of ABI is in younger men or younger males aged between 15 and 24 years. That is the highest age bracket of people that we will see presenting with trauma from an ABI. There are still a lot of people 18 years and younger who need supports and services. Those people will generally be bed-blocking. They will be in Shenton or they will be discharged home to families that cannot cope or are dysfunctional and/or are fragmented and/or are in the central desert, in Darwin, in Esperance or wherever they may be, and they are sent home.

**The CHAIR:** So the vast majority of them are from road trauma?

**Mrs Brensell:** We talk about five key ways. Predominantly it is road trauma, but assaults are extremely common. It is probably assaults and motorbike accidents. It depends on the area. If we are looking at, say, the goldfields, it would be motorbikes, and then it would be accidents and assaults. If we are looking at Perth, we are probably looking at assaults, falls and road trauma—motor vehicles. It depends on where we look in WA. Road trauma is definitely significant. The five key areas are stroke, disease, drug and alcohol misuse, motor vehicle accidents, assaults and neurological diseases and infections. There are a range of ways in which people are going to attract or potentially get an ABI, and it is post birth—anything post birth that occurs to the brain—ABI.

**Mr C.D. HATTON:** Is one of your primary roles to find accommodation? Is it a merry-go-round?

**Mrs Brensell:** Definitely. We work closely with Brightwater; however, it has a limited number of beds. It is also a business and a service provider. It is about being able to work with someone to achieve outcomes. For people who are catastrophically injured and have difficulty, there would be lack of motivation, for sure, but they would have few rehabilitation outcomes and their choices would be zero to limited. There is Marangaroo, but having talked to families about where their younger person wants to go, it is not Marangaroo.

**Mr C.D. HATTON:** What is Marangaroo?

**Mrs Brensell:** It is a facility managed by Brightwater that caters for people who need extremely high care.

**Dr A.D. BUTI:** With regards to service providers and agencies that provide care, I gather from the NDIS debate over the past couple of years that while some service providers are very supportive of the NDIS, there is a little bit of reservation. Is that because the whole of idea of the NDIS is that the money goes to the person or the family and that they lose a source of revenue or a source of control?

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**Mrs Brensell:** Definitely. It was one of the key instrumental issues that service providers were facing. There was the slow introduction of what is happening in the state with individualised services, self-directed services and My Way, but largely WA service providers, particularly the larger ones, are able to heavily influence what happens and they are able to maintain connections directly with the commission and directly with the minister. They have strong influence. There are probably a handful of the bigger players that are at the table every single time and they do have first and foremost their businesses as their primary concern.

**Dr A.D. BUTI:** So there is a club? There was criticism in the industrial relations sector a few years ago that there was a club. Do you think there is a disability services club?

**Mrs Brensell:** We could call it a purple circle, we could call it a circle of security—we could call it a lot of things. I suggest it does exist.

**Dr A.D. BUTI:** Thank you for your honesty. Does the same problem exist in the CAP process?

**Mrs Brensell:** I have no idea. The CAP process and how it manifests and who controls it is a secret. It has eluded most of us for a very long time. It lacks transparency and we do not know who is involved in the process, what the attrition rate looks like and where they get them from. We do not know much about who they are and what they know or do not know.

**The CHAIR:** The chairman of the assessment panel will be in shortly. If you could ask her one question, what would it be?

**Mrs Brensell:** Why do we not have more transparency and why do families not know and understand exactly what the process looks like prior to applying?

**The CHAIR:** We have had a lot of discussion about and submissions on the traumatic nature of the application process and how it wears people down. They have to put a grim light on everything and that in itself is pretty depressing let alone then missing out. They have a mindset that everything is dreadful. Is that the experience of the people you represent?

**Mrs Brensell:** Definitely. In recent years there has been a focus on an ideal coming out of the commission and messages going to families that it is about planning and that if they get money, they are ready to go. Yet for people who apply it is critical, it is urgent, they are in crisis now and they generally have tried everything else. They make application and bare their soul, bare all their ugliness and still do not get in. They have no feedback as to why they do not get in and why they were not successful. I have made reference to a woman and one of her comments in our submission. She said that not only did she not get any feedback, which is extremely unhelpful obviously, but after she missed out in the latest round she rang up for feedback. The response was “How many years have you been in the system?” She is into the second year and there was the notion that she probably had another year or two to go before she would be successful

**The CHAIR:** That is not actually what Dr Chalmers told us. We put to him the idea of having a waiting list similar to the Homeswest list. He said that the problem with that is what happens if someone with a chronic need makes an application for the first time? If it is waiting-list criteria, their needs would not be able to be met. That is what he said. That is inconsistent with the idea of having to waiting your turn.

**Mrs Brensell:** Definitely. I am sure everyone else has said this: everyone who applies through that process is in crisis. It is critical and it is urgent. No-one is just hanging out thinking that they should apply because they are ready to go and have done some great planning in the hope that in 10 years' time they will be successful. They apply because they need it—and they need it now. If the son of one of the families I would love for you to hear from is not in the most critical of need, God I do not know who is and who will get it above him.

[10.00 am]

**The CHAIR:** Can you describe the situation for that family?

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**Mrs Brensell:** The young man was 16 when he was hit by a bus and received catastrophic injuries. He was deemed to be at fault. He has multiple disabilities. That happened January two years ago, so it is just two years post trauma. He spent a year in RPH at Shenton Park in the adult stream even though he was 16. He was ineligible for Brightwater services at that point in time because he was under age. He has had a CAP in for at least four rounds. The family were extremely concerned about where he would go and what he would do. His mum and dad separated during that time and were living in different locations. The dad gave up his professional business as an architect to stay home and be full-time carer. The mum is a senior public servant who now has to work reduced hours in a part-time capacity in a substantive role to also share care. There was nowhere for him to go. He was technically bed-locking—that is, medically able to leave. The family did not want him to go to a nursing home and the young man himself was fearful. He communicates through a communication aid. It is a device that talks for him. Whether or not it is because of his brain injury, manipulative behaviours became evident and quite strong and he was very fearful. Given that he did not go into a facility, the dad agreed to take him home. Not only is dad and the family dealing with the grief and loss of a son, they are now his full-time carers. They have to maintain his therapy and drive him to Shenton Park every day where he is an outpatient. He has numerous medical operations that are ongoing. He needs intensive therapy.

**The CHAIR:** And a reduced income.

**Mrs Brensell:** We are talking two years. The dad is in rental accommodation on a carer's allowance. He used up all his savings. The mum is now part time but has to pay the mortgage on the house. We are talking about two years. This young person just turned 18 in September, and we are two years post trauma.

**Dr A.D. BUTI:** The problem with the CAP, I imagine, is that everyone who applies qualifies; but, because there is not enough to go around, only a small portion are successful. Under the NDIS, the assumption is that everyone who qualifies will be funded. Do you think that will occur?

**Mrs Brensell:** Our stance on the NDIS is that it is a once-in-a-lifetime opportunity, particularly for people with brain injuries, for two reasons. First, not only is the NDIS an insurance-based model, which obviously has significant business components attached to it—lifetime care, research and development and all those great things we hope to see—it is about an opportunity and a promise that every person who needs it will get it when they need it. But the NDIS has also promised us—I use the word “promise” loosely—a national injury insurance scheme. Obviously that time line is still a big push for us, as it is, I think, for other peaks both in the state and nationally. I would be seriously concerned if the May state budget does not show any goodwill or commitment towards seeing at least the introduction of a no-fault motor vehicle insurance scheme.

**The CHAIR:** Have any costings been done on what that might cost for individual premiums?

**Mrs Brensell:** I think there has. I am not sure whose intellectual property that is and how it will be released. There was an announcement about a year ago that was printed in *The West Australian* when Troy Buswell, the minister at the time, agreed at the Treasurers' COAG to commit to rolling out a no-fault scheme or an injury insurance scheme in WA. At that time, the paper printed an \$87 per annum increase in registrations. There has not been enough public evidence. Whether people sit in the Insurance Commission of WA, the Disability Services Commission, Minister Morton's office or wherever, they do know enough about it, and I am talking about it.

**Dr A.D. BUTI:** Has there been polling to determine the views of the general public about an \$87 premium?

**Mrs Brensell:** No. I think there is a sentiment that the buy-in needs to come from the public before it is successful. I am not convinced that anyone, should they face this situation or should they know someone in this situation, would not agree to pay a little bit more if it means that someone with a catastrophic injury is cared for the rest of his or her life.

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**The CHAIR:** Effectively that would take pressure off the health system.

**Mrs Brensell:** It is a win-win situation. The cost savings regardless of whether it is an NDIS or an NIIS across all elements of government would be massive—we are talking about employment, justice and education. It is a no-brainer.

**Dr A.D. BUTI:** I have taken particular interest in the NDIS as it has been formulated and debated over the past few years. I always thought that the NDIS was a no-fault insurance. If a person has a car accident and gets an acquired brain injury, that person will be taken care of because, as Prime Minister Gillard said, we are all one car accident away from the NDIS. I thought that it actually was a no-fault insurance scheme.

**Mrs Brensell:** No. It is our understanding—coming out of the Productivity Commission report—that the two were separated and that there would be a national scheme for people who sit outside of a catastrophic injury and a national injury insurance scheme, which is still a federated model, would be rolled out and that everyone and every state agreed and signed up to that.

**The CHAIR:** So that is like the TAC in Victoria?

**Mrs Brensell:** Yes. It is just WA that is dragging its feet on committing to it and rolling it out. Having said that, we are still quite some time away from the NDIS as well. We know these things take time. We are a good six or seven years into this movement of families uprising and pushing for an NDIS. We are some six years away from seeing something really tangible. Having said that, a no-fault motor insurance scheme in WA is achievable now. It was achievable last year and it was probably achievable the year before. I do not understand why there is that blockage other than potentially what it might mean at the polls.

**The CHAIR:** Can you give me an idea about unmet needs? It is one of the things that we are trying to get a handle on for this inquiry. For example, how many people with ABI would not apply for CAP places from having given up.

**Mrs Brensell:** The majority of people with an ABI would not even be interfacing with the commission and would not know about a local area coordinator. Some of them potentially would not even be eligible, to be honest. But those who are eligible are probably tied up well into other systems, predominantly justice, homeless and/or health. Based on population data, we estimate that nearly 57 500 people in Western Australia have an ABI. We know that the commission only supports—or has registered with it or is known to it—maybe 23 000 people in Western Australia. I used the figure of 57 500 just for ABI, let alone the number of people in our community who have intellectual disabilities, ASD, physical disabilities and sensory disabilities.

**The CHAIR:** What is the typical case of someone who would not be eligible?

[10.10 am]

**Mrs Brensell:** It is probably someone who is able to maintain employment, drive a car, hold down everyday living tasks and have a supportive family around them and have no need predominantly for direct care support or respite.

**The CHAIR:** One of the things you said about the CAP process is that it is solely based on written material. Do you think there should be interviews or home visits? What additional things need to happen?

**Mrs Brensell:** There is definitely an inability for people with disabilities to actively participate in that process for a variety of reasons. Sometimes they are so severely disabled that they cannot or it may be that the application is made on their behalf because the family wants something for the individual. It is unfortunate that people with disabilities are not as active in the process as potentially they could or should be. Given the sheer numbers, I am not sure how it would work logistically, but there definitely needs to be a better way of gaining an understanding of what life is



really like for those individuals and their families. It certainly will not come and does not come consistently from local area coordination.

**The CHAIR:** In addition to the insurance scheme we have talked about, what other issues are a priority?

**Mrs Brensell:** Data collection—without a doubt. When we talk about unmet need, we do not collect or share good data. It is certainly not shared responsibly and effectively across sectors and across services. It is definitely about a lack of access and a lack of knowledge of what happens in regional and remote locations. The number of people with disabilities, particularly those with ABI, living outside the metropolitan area is significant, particularly in Aboriginal communities.

**The CHAIR:** Is there also an issue with culturally and linguistically diverse communities?

**Mrs Brensell:** Yes, definitely. Their interface would be non-existent, particularly with Disability Services, for a variety of reasons. I probably use Indigenous and CALD interchangeably but, without a doubt, their understanding of and accessibility to the system and/or the processes and their lack of independent advocacy particularly. There are some great organisations. We do a great job and we work as best we can, but independent advocacy and ensuring that the message is out there and that there is an independent voice is definitely forgotten and not as widely advertised as much as it should be.

**Mr M.P. MURRAY:** This case study is turned around a little and faces the opposite way. The person has a brain injury and is in a wheelchair after having a motorbike accident. He lives at home with his aunt being his primary carer. He has to present as an outpatient at a country hospital where, at times, he becomes agitated. Now they are saying that they are going to take the aunt's guardianship away and place him in a home. How is that possible, with system going backwards? He does not want to go. He can express himself and can talk very slowly and he has a carer. However, because some people in the health system do not want to deal with him, they are trying to have him committed to a home. Firstly, I did not think that spots were available; and, second, sometimes health professionals just have to put up with these people. He will not do a lot of damage because he cannot walk. He might wave his arms around. It is the reverse of what you said. The system is trying to push him back the other way.

**Mrs Brensell:** Definitely that happens all the time. It happens, firstly, because there is a lack of awareness of what ABI is and what it means for the individual. Similarly, with the medical model there will still be a lack of understanding and awareness of exactly what an ABI is and what it means for the person. Also I would suggest that there are probably other things going on if people are suggesting that guardianship is in question. Having said that, the State Administrative Tribunal will obviously investigate the matter and determine it appropriately. But it is around the level of commission: what level of commission does the young person have to be able to make an informed choice? That is where the play comes into it. What genuine capacity does he have to make those decisions? It is extremely difficult to determine that when a person has brain injury, and sometimes it is easy to challenge it. It does obviously depend on the part of the brain that has been damaged, but that is a general excuse.

**Mr M.P. MURRAY:** I find it strange that we cannot find places for people going one way, but if a determination is made we can find a spot.

**Mrs Brensell:** There are always spots.

**Mr M.P. MURRAY:** There is always a spot!

**Mrs Brensell:** There are always spots for people who have multiple, challenging and complex needs. Nine times out of 10, those places are in the federal aged-care system. It is not a state-based system service provider.

**Mr C.D. HATTON:** So there is always a spot, but it is not appropriate

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**Mrs Brensell:** It is definitely not appropriate for any younger person to be placed in a nursing home.

**The CHAIR:** Thank you very much, Lee-Anne, for your submission and for appearing before us today. I particularly like the quotes in the submission. I suspect that some of them will appear in our report. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 days from the date of the letter attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence. Thanks very much for your time today.

**Mrs Brensell:** Thank you.

**Hearing concluded at 10.17 am**

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