



LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

**STANDING COMMITTEE ON HEALTH, AGEING
AND COMMUNITY SERVICES**

(Reference: [Inquiry into maternity services in the ACT](#))

Members:

**MS B CODY (Chair)
MRS V DUNNE (Deputy Chair)
MS C LE COUTEUR**

TRANSCRIPT OF EVIDENCE

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**Secretary to the committee:
Mrs J Moa (Ph: 620 50136)**

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

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Privilege statement

The Assembly has authorised the recording, broadcasting and re-broadcasting of these proceedings.

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Amended 20 May 2013

The committee met at 10 am.

MOORE, MX CLARE, Chief Executive Officer, Women with Disabilities ACT

THE ACTING CHAIR (Mrs Dunne): Good morning, and welcome to the second public hearing of the Standing Committee on Health, Ageing and Community Services inquiry into maternity services in the ACT.

Before we proceed I would like to take a moment to acknowledge that we meet on the lands of the Ngunnawal people and I pay my respects to elders past, present and emerging, and to the continuing contribution of their culture to this city and the region.

Today the committee will be hearing from four groups: Women with Disabilities ACT, PANDSI, Safe Motherhood for All, and the Women's Centre for Health Matters. On behalf of the committee I would like to thank all witnesses for making time to appear today. I remind witnesses that the proceedings are being recorded by Hansard for transcription purposes, and will be webstreamed and broadcast live.

I welcome our first witness today, Mx Moore, from Women with Disabilities ACT. Thank you for appearing today and for your written submission to the inquiry. I remind you of the protections and obligations afforded by parliamentary privilege, and draw your attention to the pink-coloured privilege statement that is on the table. Can you confirm that you have had an opportunity to read it, and that you understand the privilege implications of the statement?

Mx Moore: I have, yes.

THE ACTING CHAIR: Thank you. Before we proceed to questions from the committee, I would like to note that the committee has decided not to disclose the names of medical officers, midwives and doctors, and witnesses need to refrain from identifying medical officers while giving evidence. Mx Moore, would you like to make an opening statement?

Mx Moore: I would like to make an opening statement. More people with disabilities are choosing to exercise their rights to become mothers, not just women but trans and gender diverse people with disabilities, too.

Under article 23 of the Convention on the Rights of Persons with Disabilities, it is the obligation of states parties to take effective and appropriate measures to ensure equitable access without discrimination to things relating to marriage, family, parenthood and relationships.

There are a number of issues that affect people with disabilities who wish to become mothers. Women with Disabilities Australia summarises these as discriminatory attitudes and prejudicial assumptions, lack of access to information services and supports, services providers' lack of knowledge and understanding of disabled women's maternity needs, removal and/or threat of removal of babies and children by authorities, and a lack of research and data.

These issues are in addition to the barriers already faced, such as social isolation, poverty, poor community support, lack of physical access and medical discrimination. Our maternity services need to ensure that they are catering to the full diversity of disability and gender in their services. Currently, the ACT is missing that mark, as we have outlined in our submission.

Today I would like to draw your attention to some areas for action that will improve maternity services for mothers with disability in the ACT. Firstly, training: Women with Disabilities ACT would like to see investment in training for all staff at the CaTCH program, the MACH programs, Calvary and Centenary hospital, in disability sensitivity. This training needs to shift the focus away from a medical deficit based model of disability towards a more social model.

Further, training for midwives and nurses needs to acknowledge the risk of poverty, isolation and violence for women with disabilities during pregnancy and account for this in care. Consumers need to be partners in their care, especially women with disabilities, as they are often experts in their needs, but their preferences are often ignored. Training and procedures need to be updated to accommodate flexibility in care for women with disabilities and allow them to meaningfully participate in their care, which is supported by the royal college of obstetrics and gynaecology. We suggest that these improvements should be made in consultation with the community, and WWDACT can assist with such consultations.

My second point is around the support for mothers with intellectual and learning disabilities. ACT maternity services needs to help provide appropriate antenatal and post-partum support for people with intellectual disabilities who are becoming parents to help to minimise and eliminate the practice of child removal. The current high rate of involvement with child protection systems suggests that there is a significant gap in effective services for parents with intellectual disabilities. Research indicates that intellectual disability is not an indicator of parenting performance. Efforts should be made to actively combat this prejudicial assumption in our systems.

In order to fully exercise their right to become parents, people with intellectual disabilities need to be provided with appropriate information and supports, beginning during pregnancy.

Women with Disabilities ACT would suggest looking to the examples set by the BOLD Network—Better Outcomes for Parents with Intellectual Disabilities—from WWILD in Queensland. Additionally, the healthy start program from the Parenting Research Centre provides evidence-based resources on working with parents with intellectual disabilities and how to implement supportive programs from the outset.

My third point is around improving continuity of care. Continuity of care was a huge issue raised with us. Women with disabilities are looking for a clear path from their GP to prenatal care, to the maternity centres and in-home supports. But there is very little clarity in the system as it stands.

In the stories we heard, GPs were unable to refer women in a timely manner, if at all, to the CaTCH program or direct women to appropriate disability supports, which caused them to miss out on supports they needed in their entirety. Some clinics

refused flexible arrangements such as home visits, or over-the-phone appointments, which delayed care to women with barriers to transport. Additionally, the CaTCH program and birth centre do not always consider women with disability a priority, so they may be left out despite their need for that support. Sometimes this preclusion is because women with disabilities are assumed to have additional support needs, without a necessary basis. This has the effect of leaving them without any support.

It is important to note here that women with disabilities are most often from low socio-economic strata and do not have the luxury of choice in maternity care providers.

After birth our members expressed that they would appreciate better and more consistent follow-up supports from midwives and other professionals. Given the social barriers we have cited, it should be a priority to continue supports during the transition to home life. Those who had good experiences—and there were several—said that they would appreciate flexibility in follow-up appointments, such as over-the-phone and home visits. When those did occur, they were greatly appreciated.

Furthermore, continuity with the NDIS and community supports after birth needs to be improved to prevent mothers from having to remain in hospital or returning home without the aids and equipment they need. There is currently a major gap between the health system, the expectant parent, the NDIA and service providers. We would like to see efforts made to address this gap by maternity services.

My last point is around information provision. Several of the barriers I have talked about today can be helped by better information provision from maternity services and also in the community. Women with Disabilities ACT could be funded to complete a project to create accessible resources on maternity care, as well as on aids and equipment available within the community from other services.

This can draw on the experiences of mothers in our community, to share with prospective parents in the ACT and region. This could work with the upcoming Women with Disabilities Australia virtual centre, which is a national project, which will have resources available as well, and that will link to national information.

I thank you for the opportunity to provide our perspective and I hope that you consider it.

THE ACTING CHAIR: Thank you very much for your submission and your very comprehensive opening statement, which covers a lot of the field. In your organisation, what types of disabilities do you come across? Do you think you come across the full panoply or are you more likely to deal with people with physical and mobility disabilities? Could you elaborate?

Mx Moore: In our membership we cover the full spectrum: physical, intellectual, psychosocial, sensory. All of those are within our membership.

THE ACTING CHAIR: You are a membership-based organisation?

Mx Moore: We are a membership-based organisation.

THE ACTING CHAIR: With that big panoply of different sorts of disabilities, are there stand-out areas? Ms Le Couteur and I were on another committee where people with disabilities spoke about a lack of physical access, for instance, the examination beds being too high and things like that. Are there stand-out issues which are easy fixes and other things which are much more complex?

Mx Moore: Things like those physical access issues are still issues, but they would be perhaps in the easier fix area, because they are better known. The issues I am talking about around navigation of the system tend to be more cryptic. That is why I am drawing attention to them here.

MS LE COUTEUR: Why do you think we have not fixed the easy ones, the physical ones? I agree with you that they would appear to be fairly straightforward.

Mx Moore: That is a very complex question. Partially it comes down to cost, but also the barriers to motherhood that I speak about mean that there have been low rates of women wanting to become mothers because of those barriers. As we break down those barriers, more and more women will want to become mothers, so we are slowly drawing more and more attention to the barriers that remain here.

MS LE COUTEUR: Is the interaction between the health system and the NDIA part of the problem? I am not an expert on the NDIA—you would be—but my understanding is that they basically do not fund health things, and I assume that they might well regard pregnancy and maternity as a health thing, not a disability thing.

Mx Moore: As it stands, there is no clarity about what the NDIA would cover with regard to maternity services. Indeed, it is likely that they would say they would not cover anything. I believe it is currently being talked about. This is an area where there is a gap currently. I think it would be worthwhile for the maternity services to have a dialogue with the NDIA.

In the area of community care, where again there is that tension, there has been some success in navigating that space. I think having a dialogue about being a mother being part of a lifestyle, not a health condition—so these would come under the NDIS—is a discussion that needs to be had.

THE ACTING CHAIR: Especially if we are trying to not hypermedicalise maternity.

Mx Moore: Absolutely.

THE ACTING CHAIR: One of the things that popped out from your submission was the propensity to hypermedicalise maternity services for people with a disability and that it may be one of those spaces where women get to exercise less autonomy because people have preconceived ideas about a particular disability and perhaps a lack of understanding. You have spoken about the need to educate people in maternity services generally about providing a service to women with a disability, but also you have said that it needs to be quite specialised, depending on the client. What sort of information are you looking to see produced, whether it is through your organisation

or more generally?

Mx Moore: I think guidelines around flexibility are very important, so working with a mother's existing support in terms of what other medical professionals she has, if any. Some women with disabilities do not necessarily have ongoing health interactions, and we need to acknowledge that. Many women with disabilities will not need extra medical intervention, but there needs to be flexibility which says that if someone approaches you with a particular condition, you need to talk to them: "Who are your existing doctors?" "Can we talk to them?" It is all about being flexible with what is already in place and listening to the patient. Unfortunately, because it is such a diverse thing, it is very hard to say what resources will be individually produced. I cannot offer too much specific guidance on that.

THE ACTING CHAIR: What I am also hearing from you, and what is in the submission, is that there tends to be a sort of silo: "This is maternity services and we do our thing here." In this case, there does not seem to be reference back to the community or medical support that the client might have outside of maternity services. Is that a reasonable assessment?

Mx Moore: Yes, absolutely. It needs to consider the patient as a whole person.

THE ACTING CHAIR: In the ACT, which we are primarily concerned with, as a matter of course, would a patient presenting with a physical disability automatically go into the at-risk stream?

Mx Moore: It would depend on the disability, because that would not necessarily affect the pregnancy. An at-risk pregnancy is a medical condition. It really depends on what the disability entails. Rather than considering it a medical risk, I would urge you to consider that the social factors around women with disability need to be considered, around putting them into supportive programs. Continuity of care is so important. Risks that come from being socially isolated and from having poor access to medical care are more likely to be an issue than necessarily the medical risk of being a disabled woman and pregnant.

THE ACTING CHAIR: So the follow-up, postnatal services are very important.

Mx Moore: Very, very important.

THE ACTING CHAIR: In your submission and your opening statement today, you spoke about follow-up. From your experience with your membership group, how good is it? When is it good and when is it bad? What do good and bad look like?

Mx Moore: The midwife visits with the MACH program, I believe it is. I got great feedback on those from some of our members. When they got the same midwife continuously, that was very helpful. Being able to call back and get the same person was really important. When it was not good was when you got a different person each time. Other things about it that were good were when there was flexibility in coming into the home and going "This is not quite working. Even though it does not match our traditional model of how we would help you, let us come up with a support that is going to help you as you are." It is about not trying to force a woman with disability

to use the usual supports.

THE ACTING CHAIR: So real continuity but flexibility at the same time is the gold standard?

Mx Moore: Yes.

THE ACTING CHAIR: Do you have a feel for whether women with a disability who are postnatal have requirements for longer contact? Often able-bodied women might get one or two visits if they are lucky. Is there a gold standard for how long, or is that again a personalised thing?

Mx Moore: I believe it is still a personalised thing. It depends what community supports are in place. For example, if a woman does not have the community supports in place in terms of, say, getting their equipment updated, they are going to be under more strain, and that means that they are going to need more support from the midwife side. It really depends on those wraparound services.

THE ACTING CHAIR: But it also depends on the extent to which that individual woman is connected with the community.

Mx Moore: Exactly, yes.

MS LE COUTEUR: One of the things you said was that disabled women were much more likely to be at risk of poverty and isolation. How much do you think that is impacting on the negative experiences for these women? Poverty and isolation are obviously not confined to the disabled community. I appreciate that you have two problems, but I am interested in whether you have any idea of how much the second one is a contributing factor.

Mx Moore: One of the women I talked to specifically for this submission, because of their financial restrictions could only go to a public GP who really was not an expert in this particular area and could not refer them to appropriate services. They could not switch GPs because they did not have financial means. That delayed their care and had a whole range of flow-on effects. So poverty actually had a direct effect on their maternity care through not having choices.

MS LE COUTEUR: Was that GP doing the right thing as far as their non-maternity care went? Just maternity was beyond them? It sounds quite worrying.

Mx Moore: From what I understand, it was their usual GP and they had been happy with them but it just was not the right fit at that time. But they did not have the options that women with more money have. This comes back to the issues of bulk-billing GPs in the ACT.

MS LE COUTEUR: Yes. That is a real issue, not confined to your community.

Mx Moore: It is a real issue, yes. Social isolation also becomes an issue of information provision, because so much in maternity seems to be around word of mouth. You find out about the services and things from other mothers; that is what we

heard a lot of. If you are not engaged with the community and you cannot get that information out of your medical professionals, where are you going to get it? It is not available online and it is certainly not available in accessible formats.

MS LE COUTEUR: When you say it is not available online, are you saying you cannot find out what services you could go to, or are you talking specifically about “If X happens and you are 20 weeks, then you should be concerned” or whatever?

Mx Moore: Both. There is minimal information available online about what maternity services provide. There is “This is a hospital and these are our procedures” but there is limited information about how you would get referred to those services and how that works. And for that pathway information there is a big barrier.

MS LE COUTEUR: Is that specifically worse for your members than for the rest of the community?

Mx Moore: I would say so, yes.

THE ACTING CHAIR: Because of the complexities of the conditions on top of—

Mx Moore: The complexities of the system on top of everything else, yes.

THE ACTING CHAIR: Drawing on your membership information, which would not be a whole sample, what patient load are we talking about?

Mx Moore: I would not be able to say confidently.

THE ACTING CHAIR: That is probably something we should take up with the directorate.

MS LE COUTEUR: Given that most of your members would have someone who supports them prior to the birth as well, how well can those people get involved? Is one of the problems that they are not being informed of what is going on so that they can be better at their support role?

Mx Moore: Possibly. The assumption that there is always someone involved is—

MS LE COUTEUR: I know there is not always but I have heard from people who have—

Mx Moore: There is a higher rate of single motherhood for women with disabilities. There is that but also we really do not want to be handing over the autonomy of women with disabilities by simply communicating with their carers. That is something we want to be very careful of.

THE ACTING CHAIR: Could I ask an egg question rather than a chicken question? You said earlier, Mx Moore, that there has been a lot of stigma about people with disabilities becoming parents and that that is, to some extent, breaking down. Does this highlight issues about fertility and capacity to conceive? Is that something you have looked at?

Mx Moore: That is not something we addressed here, because fertility for people with disabilities is not necessarily any different from the general population. There are issues around access to reproductive technologies, but that is not something we discussed here in particular.

THE ACTING CHAIR: In your membership group, is being able to become pregnant part of the complexity that you are—

Mx Moore: I think it is part of the complexity. It is just not something we dived into in this particular submission. I am happy to take your question on notice and provide more info.

THE ACTING CHAIR: As there are fewer stigmas and taboos than there have been in the past about people with disabilities parenting, people might say, “I’d like to exercise those rights” but also be confronted with fertility problems, which may be both medical and mechanical.

Mx Moore: And there are still significant barriers to accessing reproductive technologies from this stigma as well.

THE ACTING CHAIR: Stigma is an interesting thing. It was touched on lightly by a witness the other day who commented that because she was young, she felt that she was looked down upon. How much of that is an issue for women with disabilities who are presenting to maternity services?

Mx Moore: I would say it is still quite a big issue. People we spoke to said that they felt from staff, doctors and nurses, that they were looked down upon for becoming parents while disabled. That is with all manner of disability. That is also where the gender element—where I talked about trans and gender-diverse people—of discrimination comes in as well. That was quite a complex element in some of the cases we talked to.

THE ACTING CHAIR: It could also touch on the issue you raised of the level of institutional intervention in the parenting of people with intellectual or mental disabilities. How, from your experience, could we do that better, apart from not presuming that because someone has a mental or an intellectual disability they are going to be a bad parent?

Mx Moore: It starts with good supports. Every new parent needs to learn the skills of becoming a parent. But when people learn differently, we need to provide those skills in a different way. There is currently no scheme in the ACT that really provides those skills in a manner that we have seen elsewhere. The healthy start program I talked about is what I would see as a really great standard. Providing that kind of support would be a really good step in the right direction, a preventative step, because at the moment we are addressing it once things get to the care and protection stage and appealing decisions already made.

THE ACTING CHAIR: As you say, we all have to learn how to be parents. Some people learn from their extended family. That is less and less the way people learn

these days, because there are not big families, multigenerational families, where you learn your skills from your aunties or cousins or whatever. But when you add to that the aspect of isolation of people with a disability, that makes that learning perhaps even harder, and they may not be supported in their family to make these decisions.

Mx Moore: Absolutely.

THE ACTING CHAIR: There is lots of food for thought. Thank you very much for your very thoughtful contribution today. After this hearing you will receive a proof transcript of the *Hansard* to review. If there is anything that needs to be clarified, you can take that up with the committee secretary.

LUXFORD, DR YVONNE, Chief Executive Officer, Post and Ante Natal Depression Support and Information

THE ACTING CHAIR: Thank you for appearing today and for PANDSI's written submission to the inquiry. I remind you of the protections afforded by parliamentary privilege which are set out in the pink laminated statement. Can you confirm for the record that you have read and understood the privilege statement?

Dr Luxford: Yes, I have.

THE ACTING CHAIR: Before we move to questions would you like to make an opening statement?

Dr Luxford: Yes, I would. Especially as it is NAIDOC Week, I acknowledge the country that we are meeting on today, acknowledge elders past, present and emerging, and thank the Ngunnawal and Ngambri people for caring for this country so well over time. Thank you also for inviting us to speak today. We really appreciate that opportunity. Thank you for the opportunity to share some ideas with you today.

As a bit of background, PANDSI is an accredited mental health service which specialises in the care of parents experiencing mental health issues from pregnancy through to when their child reaches the age of two. We individually assess each client and we develop a plan of support to best meet their needs, including ongoing telephone counselling, workshops and group sessions which focus on developing tools and strategies to best manage their problems.

Perinatal mental health problems can make the lives of new parents overwhelming, isolating and even unbearable and can lead to long-term issues for all family members if not addressed. At least 15 per cent of all new families are struggling with these problems and around 20 per cent of PANDSI clients have endured a traumatic birth experience.

At PANDSI we have great respect for the work of health professionals caring for parents before, during and after birth. We understand that they are working in difficult circumstances and are often stretched due to scheduling and lack of available staff. We believe in a holistic approach to care which focuses on mental and physical wellbeing and would like to propose some recommendations that have the potential to prevent mental health problems developing, lessen their impact or identify problems early to enable supports to be quickly put into place.

We recommend that the current continuity of care midwifery programs be continued and expanded with ongoing support for the birth centre; that parents have an opportunity to debrief about the birthing experience with a midwife in the hours or immediate days following the birth; that screening for perinatal mental health vulnerabilities occur at the first appointment a pregnant woman and her partner have with a health professional and continue to occur at regular periods of time antenatally as an expected part of visits to the midwife or doctor, whether in the public or private system; that all midwives, GPs, obstetricians and maternity and child health nurses be appropriately educated in perinatal mental health; that the ACT government advocate

to the federal government to increase the number of claimable visits to a psychologist for people with a mental healthcare plan; that all antenatal classes include education in mental health and emotional wellbeing in the lead-up to birth and afterwards; that additional funding be provided to MACH nurse services to support a series of home visits at six days, six weeks and 16 weeks with a specific focus on the health of the mother and baby rather than the usual emphasis on the baby's growth and development; that a dedicated unit in Canberra for mothers requiring residential mental healthcare be established for women to access both antenatal and, where possible, with their baby after the birth; and that the ACT government fund a sustained awareness-raising program using social and traditional media to increase understanding of perinatal mental health at a population level and to increase the number of people seeking help and therefore improving family wellbeing overall. That information needs to be available in a variety of community languages.

THE ACTING CHAIR: Could we talk about the client base. How many people would you see in a year?

Dr Luxford: At the moment we are only able to care for around 350 people each year. We are restricted by funding obviously, yes.

THE ACTING CHAIR: This is a how-long-is-a-piece-of-string question. How much unmet need do you think that there is?

Dr Luxford: At least three times that.

THE ACTING CHAIR: I heard you on radio this morning saying that you probably needed three times the funding—which is? How much is your ACT government funding at the moment?

Dr Luxford: From the ACT government? It has just gone up, which is lovely, thank you. I must say thank you for that. At the moment it is just under \$700,000.

THE ACTING CHAIR: You think that needs to triple or to quadruple?

Dr Luxford: I would love it to quadruple but to triple just to meet the need. When you look at 15 per cent of births—if we have got just over 6,000 births a year—annually we are having that increase and we will often care for somebody from shortly after birth or even before birth while the mum is still pregnant right until the baby is aged two. That is not in all cases. Often they are well enough to cease using our services before then. But if you look at the worst case scenario we could be caring for somebody for close to three years.

MS LE COUTEUR: How much non-government funding do you get? Obviously I am aware of some of your fundraising activities. Is this significant?

Dr Luxford: We were really lucky this year. You obviously have heard of cake-off. We were very lucky this year with cake-off in that we raised just under \$72,000, which is absolutely wonderful. That includes a generous matching grant of \$25,000 from the ACT government. We greatly appreciate that as well. That finishes next year.

THE ACTING CHAIR: Can people donate to you? Are you a charity for—

Dr Luxford: They are very welcome to donate to us.

THE ACTING CHAIR: Do you have charitable status as well?

Dr Luxford: We have charitable status, yes.

THE ACTING CHAIR: You have a philanthropic arm as well, a fundraising arm?

Dr Luxford: Yes. I balance between managing the mental health service and fundraising. It is an interesting balance.

THE ACTING CHAIR: On the basis that 15 per cent of births would result in some level of perinatal mental health, and you are seeing one-third of those people roughly, of the 15 per cent—getting back to my initial question—how many would benefit from a residential service at some stage in their illness?

Dr Luxford: That is a really interesting question and I do not think I can answer it with an exact number. In terms of the recommendation, we were thinking more of when people are being admitted to an in-patient mental health facility for a mental health problem that may or may not be related to the birth. It may be something completely different. At the moment there is no opportunity to take the baby with you. That was more what we were looking at then.

Having said that, another type of in-patient facility, such as may be offered at QEII, which is looking at sleep problems or feeding problems that could also incorporate a mental health and wellbeing aspect to it, would be really valuable and we, as an organisation, would be very happy to collaborate with the facility or the government in doing something like that.

THE ACTING CHAIR: I think we might be speaking at cross-purposes here. Your suggestion on residential was about people with a mental illness that may or may not be birth related but those who have children have been able to take their child with them, which you cannot do in the adult mental health—

Dr Luxford: You cannot do it at the moment. That is right.

THE ACTING CHAIR: It is probably not an ideal environment for anyone in those circumstances, on either side. That was not quite what I thought you were proposing. What I was asking about—and thank you for that—was this: is there a need for a postnatal depression specific residential service in the ACT? I do know that from time to time women have to travel interstate because we do not have a residential service here.

Dr Luxford: Any service that can help families at that time would be valuable. I cannot say that we have actually surveyed the need for a residential service at this point that is specifically related to perinatal mental health problems. As I said, any additional service that was available would be beneficial.

THE ACTING CHAIR: Would you have at your disposal, and possibly on notice, figures on the number of people who might go through your casebooks who might end up travelling interstate for residential services?

Dr Luxford: We could certainly look at our data for that, but I am not sure that many of our clients do actually need to travel interstate for residential services, I have to say.

THE ACTING CHAIR: But it is not a no?

Dr Luxford: It is not a no. Off the top of my head, and thinking about our clients, I am not aware of clients needing to travel interstate for residential reasons—

THE ACTING CHAIR: With the unmet need that PANDSI sees, where is that being treated? If the people are not coming to PANDSI, where are they going, or are they going nowhere?

Dr Luxford: I think they are often going nowhere. There was a recent study released in the US, a month or so ago, where they looked at the costs of what they called perinatal mood and anxiety disorders. They found that over half of women who actually have a diagnosis of perinatal depression are not getting any treatment whatsoever. They must have seen a health professional at some point to get that diagnosis, but they are not getting any level of treatment. They are costing the need that is not being met at the moment around that at \$US14.2 billion, for one cohort over five years—the mother and baby cohort—due to the problems that that can cause without people receiving care.

Having said that, people are receiving care from other avenues in the ACT. They may be receiving care from the government service, the perinatal mental health consultancy service, although they have a waiting list and they can only see you until the child is aged one. They cannot help partners; it is only for the birthing mother. They could just be seeing their local GP or they could be seeing a psychologist. That is one of the reasons why we have recommended that we extend the number of visits that you can have with a psychologist under the current program.

Often they are doing all three, and seeing us. We do refer between one another. I have to say that in the ACT people do work very well together and there is a lot of collaboration and referring. You do not need a referral to come to PANDSI; you can just phone us.

MS LE COUTEUR: Do you find that the people who need you actually find you? You said there was a lot of information, but I would imagine that quite a few of the people who could be helped by you would not be in a position to find out.

Dr Luxford: That is true. I think there are a lot of people who do not hear about us. When they do, they are very happy. We are constantly getting that message from new clients, who say, “I wish I’d heard about you earlier.”

Unfortunately, there is a limited amount of awareness raising that we can do. We do what we can. Of course, we jump on media opportunities with cake-off to try to raise

that awareness. One of the purposes of cake-off is not just raising money; it is also awareness raising, obviously.

THE ACTING CHAIR: The risk, of course, of raising awareness is that you cannot meet the expectation.

Dr Luxford: It is a problem. At the moment we are having to increase the number of first-visit interviews, what we call intake interviews in a day, which is stretching our staff, in order to manage that increase in inquiries.

MS LE COUTEUR: I assume there is no cost for your clients?

Dr Luxford: No, there is no cost. We do run some psycho-educational and physical groups, such as yoga, which is great, a fitness support group, which has the two aspects built into it. We ask for a small payment for that when we bring in physical health experts to run those programs. Again we will wipe any costs if needed.

MS LE COUTEUR: One of the things that shocked me in your submission—I suppose it was a matter of ignorance—is the number of men who have antenatal depression. You said up to one in 10 fathers, partners, experience postnatal depression. Are you finding it easy to contact the male—

Dr Luxford: No.

MS LE COUTEUR: I was really surprised to see that statistic. Obviously, I am aware of mothers with postnatal depression, but with fathers, generally, you think that there is a lack of sleep for a bit, but it is not at the same level. How do you deal with that?

Dr Luxford: It is an interesting statistic, isn't it?

MS LE COUTEUR: Yes.

Dr Luxford: There has not been a lot of research done on partners antenatally. The research is much stronger on numbers postnatally. I think it is often not recognised. One of the issues is that, in antenatal classes, we need to make people really aware, not just of the physical things leading up to birth—breastfeeding et cetera—but of their mental health and wellbeing during pregnancy and afterwards—what is normal and what is not normal—so that you recognise when something is not going well, and it is not just that you are exhausted. As we know with a lot of mental health problems, it is not uncommon for men to self-medicate through that, through increasing alcohol intake et cetera, rather than actually recognising the problem and dealing with that problem.

MS LE COUTEUR: Given that you have nearly the same numbers of male and female partners, do they tend to be couples who are both having issues?

Dr Luxford: They can be. We do have some clients where we are helping both the mum and the dad. That is becoming more common than it was previously. Fortunately, we are seeing more partners, which is a good thing. But at the moment, no; we are

still not seeing anywhere near as many partners as we are seeing with the mums.

MS LE COUTEUR: Or the dads individually?

Dr Luxford: We do see some of the dads individually. We tend to, with the dads, rather than group sessions, partly because of employment preventing us from having group sessions during the day, help them through telephone counselling, ongoing telephone calls, or even email support. Email support can work really well with the partners. We run what we call partners' information evenings on a regular basis, probably once every school term, that kind of regularity.

It is interesting, when you get in a number of the partners of our current clients, and it is really in order to educate them about how they can better support the mum, that they start to recognise things in their own mental health and wellbeing that mean they could do with some self-care.

MS LE COUTEUR: You quoted a statistic, you said from AIHW last month, which demonstrated that in 2016 suicide was the most common cause of maternal death, which I find, obviously, horrific. Is that the same in the ACT? Is this a statement for the ACT as well?

Dr Luxford: That is the statement for Australia wide.

MS LE COUTEUR: Just Australia.

Dr Luxford: They did not give specific data for the ACT because of the issue of the small population. I did try to get ACT data, and it was not available.

MS LE COUTEUR: Would you have any reason to believe that we are different from the rest of Australia?

Dr Luxford: Unfortunately, no.

THE ACTING CHAIR: Could I just go back to the men for a while. Do you see fathers, partners, whose partners are not your clients? I know that you do. What proportion of the men that you would see would be men whose partners are not your clients?

Dr Luxford: It would not be—

THE ACTING CHAIR: It would not be many.

Dr Luxford: It is not very many but, having said that, fathers and partners are quite a small percentage of our client base in any case. We certainly do see partners and fathers, either where the mother, let us say, is not the client or where they are clients in different time frames, when their mental health problems occur at different times.

THE ACTING CHAIR: But your service cuts out when the child is two.

Dr Luxford: Yes. Most services cut out at one. We definitely want to keep going, to

look after them until they are two.

MS LE COUTEUR: My understanding is that you started off very much in terms of peer support, but maybe I am wrong.

Dr Luxford: Yes, 30 years ago.

MS LE COUTEUR: How much is that still part of your model of care?

Dr Luxford: That is a really interesting question because now, obviously, we are an accredited mental health service.

MS LE COUTEUR: You are a professional organisation.

Dr Luxford: It is a very professional organisation. The care that we provide directly is not on a peer support basis, with professionally trained counsellors et cetera. However, because of the nature of the groups that we run—you stay in your group setting for an eight-week period; it is a group that you commit to for eight weeks—there is an incredible level of peer support that develops. We have also started fostering that through holding sessions such as meet and mingle sessions where the attendees have set up Facebook messenger groups and are messaging each other before they have even left the room, which is just fantastic.

That level of support between one another within a cohort is really important and continues on. It is not uncommon after a baby and me yoga session that that group will go and have a coffee together after the debrief. That ongoing support occurs, but it occurs in an organic way that we foster. But we no longer run a peer support program.

MS LE COUTEUR: Would that be a way of expanding your services or is it not something you have thought of?

Dr Luxford: It is something that we have thought of, although what is really needed is the professional support that we offer. Peer support on potentially a volunteer basis would be a great adjunct, but I would not say that that would be where we need to grow at the moment.

MS LE COUTEUR: Our previous speaker—you heard most of it—made a comment that one of the bigger issues for their clientele was poverty and isolation. Clearly that is not restricted to the disabled community. How much of that would seem to be an issue for your clientele?

Dr Luxford: It is definitely something that we see at the moment. To the extent that not all clients can attend groups, can get to us, we provide a taxi service if needed, but that is an extremely expensive way to move people around. We will organise and pay for a taxi if somebody cannot get to a group; that is something that we have covered off.

In terms of isolation, it is very much a chicken and egg issue. Isolation itself and feeling that lack of support can lead to the development of anxiety and depression. We

are starting to see more families from diverse cultural groups who are experiencing that social isolation of being away from home, having come here and being in a completely different culture. I had a very interesting conversation with somebody who said that where they came from, which I think was Bangladesh, everybody had the same culture. When you come to Australia it is so multicultural. That in itself is quite a surprise that you need to deal with. It is a different way of seeing the world and a different way of finding your place within it. It can be very isolating when you feel that you are just trapped in your little bit of it.

MS LE COUTEUR: Are CALD families, culturally and linguistically diverse families, underrepresented in your clientele?

Dr Luxford: They are underrepresented. We are doing what we can to increase that representation. We are running workshops with different CALD groups and we are upskilling our staff in the use of interpreters in understanding the different requirements and expectations of different cultural groups. We are reaching out as much as we can and we are also running programs, where we can, in different locations where we might meet more people with cultural diversity, such as up in Gungahlin.

THE ACTING CHAIR: Could I go back to some of the issues you raised in your opening comments and on the radio this morning: screening at the very first appointment.

Dr Luxford: Absolutely.

THE ACTING CHAIR: Are there screening tools?

Dr Luxford: Yes. There is a great tool called the Edinburgh postnatal depression scale that we use within the program. It is used worldwide and it has been validated in a variety of different languages, so it is useful with all groups. That is a great tool that can be easily administered, whether by a GP, by a midwife or antenatally. It is certainly a risk factor that if a parent has experienced mental health problems previously they are likely to be exacerbated during pregnancy or they may have a higher risk of anxiety and depression during pregnancy which may not be picked up at all: everybody thinks it is just a hormonal thing where you are on this little whirlwind, whereas in fact it could be masking some mental health problems that could be easily treated.

THE ACTING CHAIR: So we do not have to reinvent the wheel?

Dr Luxford: We do not have to reinvent the wheel.

THE ACTING CHAIR: And you would advocate that that screening test might be administered a number of times antenatally?

Dr Luxford: Yes, antenatally and postnatally.

THE ACTING CHAIR: And then at six days, six weeks, and 16 weeks? Would that be part of the MACH nurse visits at those times?

Dr Luxford: It would be great if it were part of MACH nurse visits. I know that MACH nurses do ask mums, and dads if they are home, how they are feeling themselves. We get a number of referrals from MACH nurses as well, and MACH nurses often ask clients to self-refer to us rather than referring them directly. I also know that the MACH nursing service is quite stretched itself. They have a lot of people to see. It is an opportunity where potentially an organisation like PANDSI could be coming in and making those visits that are focused specifically on the mental health and wellbeing of the parents, with three home visits per family. I think that that would be an amazing thing to implement.

THE ACTING CHAIR: The other thing you spoke about was debriefing. Could you elaborate a little on that?

Dr Luxford: Wouldn't it just be wonderful if you got to talk through the birth after the birth? Today is my daughter's birthday, so I am thinking back to 20-odd years ago, remembering very well what I went through with her birth. And every mother and father remembers what they go through. Opportunities to debrief with the midwife directly after the birth, within hours after the birth, could, I think, go a long way to calming any anxiety that people may have, and also to inform them about anything that might have gone wrong.

Things do go wrong—we know that—and we have amazing health professionals who are there to help in those situations. But often it is not made clear to the parents what has happened and what to expect, and they are not kept informed along the way as well. Those are some of the things we hear from our clients. As I said, at least 20 per cent of our clients have experienced some level of birth trauma. Often that trauma has been enhanced because they have not been informed of what was going on. They have not been kept informed or there was no debrief afterwards.

THE ACTING CHAIR: Sometimes it is difficult in the heat of the moment to be really communicative, but that should be compensated for afterwards by talking through it.

Dr Luxford: Absolutely.

THE ACTING CHAIR: It seems blindingly obvious when you say it that if you give people that opportunity then there might be something like, "I didn't expect X to happen." It may be that they did not expect X to happen but X happens all the time, and then they perhaps will not dwell on that. If they hear, "That's par for the course," then that is possibly something they are less likely to dwell on.

Dr Luxford: Exactly.

THE ACTING CHAIR: So you have an opportunity to ventilate things that may have gone well or may have been unexpected, even when you have a good birth outcome.

Dr Luxford: Yes. It is a fairly easy thing to incorporate into the everyday way of being in the hospital or wherever the birth is taking place. I think it would be an easy

thing to add in. But it is something that needs to be incorporated as a tick-off, where you are going to sign off that you have done this, rather than being an add-on. If it is an add-on, it is not going to be done. It has got to be part of the normal processes.

THE ACTING CHAIR: Part of the thing is that with the birthing centre you go home very quickly, or if you stay in the antenatal wards you are not seeing the midwives who delivered; you are seeing another set of midwives.

Dr Luxford: That is right.

THE ACTING CHAIR: So there has to be some crossover of care in that space. Following on from that, you are saying that 20 per cent of your client base have had traumatic births in some way or another. That means that 80 per cent of people might have sailed through their pregnancy and delivery, but they still hit a wall somewhere along the line. We are hearing that people are not attuned to the fact that somewhere along the line the wheels might fall off, and that they often cannot recognise what is normal.

Dr Luxford: I think that is really true. As I said, we need to focus more on those issues during antenatal classes. Most parents, especially first-time parents, will attend antenatal classes. We do not focus very much on what to expect in terms of your own mental health and wellbeing: what is normal, what is not normal and what are red flags you absolutely need to be taking some action on. If we let people know gently during that time—I know it is a whirlwind of things that you are learning at that time—we can inform people then and they will remember. It will come back to them. They will go, “That’s right: this isn’t a good thing.” Again, it comes down to a broader educational campaign too. We need to be talking to the general public. Just as we are reducing stigma around other areas of mental health, we need to be drawing attention to this through a broader campaign.

THE ACTING CHAIR: Wonderful. Thank you very much for your attendance here today and your submission and your evidence. There a couple of things you said that you would take on notice. Also, you mentioned some US research about the economic burden. Could you forward that to us as well?

Dr Luxford: I will forward it to the secretary. That is not a problem.

THE ACTING CHAIR: A proof *Hansard* will be forwarded to you by the committee secretary. This gives you an opportunity to check the transcript. If there is anything there that you wish to clarify or add to, you can do that through the committee secretary. On behalf of the committee, thank you very much.

Hearing suspended from 11.05 to 11.29 am.

KIRK, MS MARY, Public Officer, Safe Motherhood for All Inc

THE ACTING CHAIR: We will resume our hearing today. I welcome Ms Mary Kirk from Safe Motherhood for All. Thank you for appearing today, Ms Kirk, and for Safe Motherhood’s written submission and the survey that you provided. I remind you of the provisions of the pink privilege statement. Have you had an opportunity to read and understand that?

Ms Kirk: I have.

THE ACTING CHAIR: Before we proceed to questions, would you like to make an opening statement?

Ms Kirk: I will make a short one, yes. I will declare that I do have an interest, as a midwife, and I am also the Vice President of the International Confederation of Midwives. I am disclosing that.

THE ACTING CHAIR: You are experienced.

Ms Kirk: I am experienced. I thank the committee for giving Safe Motherhood the opportunity to address you personally. It always adds a richness that you might not normally enjoy.

The most important thing to highlight is that Safe Motherhood for All advocates for respectful maternity care. In relation to respectful maternity care, Safe Motherhood for All holds the view that it is a human right for a woman to experience respectful care. The other term that is important is maternity care, in that Safe Motherhood for All focuses on the woman and the experience of the woman, and that the woman should be central to maternity care, not the professions. The professions, in relation to maternity care in Australia as we know it at the moment, are mostly medicine and midwifery. We believe that it is important that we talk about maternity care.

Safe Motherhood for All would also like to highlight that the clinical and psychological safety for pregnant women and mothers needs to be incorporated into the provision of care to improve women’s chances of experiencing a positive pregnancy.

We hold the view that there are lots of lenses through which safety in maternity care is provided. The principal lens that is applied in Australia today is the lens of mortality, as opposed to morbidity, and the full effects of maternity care on a woman and consequently her infant and her family. The narrow lens of holding a banner saying, “We have the safest in the world because women don’t die,” is shallow, not good enough and fails to meet the full needs of women and their families.

We hold the view, based on international evidence—global, massive studies—that pregnancy may be uncertain but it is not dangerous for the majority of women. It is safest in health systems where a woman is central to the system and safest when evidence-based care is provided with respect and in a partnership model. By that we mean that it is in models where professionals are on tap, not on top. Right now, we are

experiencing more and more professionals on top, not on tap.

The World Health Organisation was very clear that, for most people, with caesarean section rates above 10 per cent across the population, maternal and newborn deaths do not decrease, with the more and more that you provide. The evidence is overwhelming that 85 per cent of births do not require a high level of intervention, but in Australia today we are seeing intervention exponentially increasing over time.

The evidence is overwhelming that the wealthier you are and the better educated you are, the more likely you are to be healthier; therefore the more likely you should be to have low intervention. In Australia that is directly inverted: the healthier you are and the wealthier you are, the more likely you are to have high intervention in birth. It is wrong; it is just wrong. With that comes a consequence for the mother, the baby and the family. We truly believe that if the principles and practices of respectful maternity care are applied, those rates can be turned around, and that interventions can be provided readily and easily for those women that need them.

The tenet of a good health system is where services are acceptable, accessible and affordable, and close to the person who needs it. What we have is an inversion that is starting to creep in, in Australia today. We are expecting people to go further and further away from home to have their babies. The further away you get from major centres, the more likely you are to be dislocated from home and family to have your baby, despite the evidence.

There is an accessibility problem. With respect to affordability, the majority of people are spending thousands and thousands to have their babies. That should not be the case. With the interventions that are happening, the evidence says that there should be two ultrasounds in a normal, healthy pregnancy; we have six and eight ultrasounds going on nowadays. Can the health system afford it? I am talking about the affordability for the system, let alone for the individual. With respect to the aspect of being close to home, we are moving further and further away by insisting that all births happen in big centres.

We are saying that we are failing in lots of places, and that is not just globally and nationally. We can apply these tests locally and see that a woman is not experiencing respectful care, and care that optimises the outcome for her, her baby and her family. That is probably the essence of our submission.

THE ACTING CHAIR: Could I start, Ms Kirk, by asking you a little about Safe Motherhood for All? Is it a membership-based organisation? Where do you attract your membership from?

Ms Kirk: It is an offshoot of—I do not know whether you have heard of it—the White Ribbon Alliance. In Australia we called ourselves Safe Motherhood because of the White Ribbon group. The international White Ribbon—

THE ACTING CHAIR: I was confused by that, in your submission. I thought—

Ms Kirk: “Hang on a minute; where’s the connection?”

THE ACTING CHAIR: Yes, because “white ribbon” means something else in Australia.

Ms Kirk: “White ribbon” in Australia means something else, but “white ribbon” internationally is about respectful maternity care. It is a large global organisation. Safe Motherhood for All is the Australian equivalent, and it is a member organisation. It is open to anyone who is interested in safe motherhood.

THE ACTING CHAIR: It is not an organisation of health professionals?

Ms Kirk: No.

THE ACTING CHAIR: From your experience, where in Australia does the membership come from?

Ms Kirk: There are health professionals—I am sitting here today—but it comes from a broad church. All sorts of people are members.

THE ACTING CHAIR: What is the governance structure?

Ms Kirk: It is incorporated as an association, and it is incorporated as an association in the ACT. It has a board, an elected board, and from there the members elect the board.

THE ACTING CHAIR: I do not know where to start with your submission and the survey. I think I will start with the survey. Something that has been a slightly top-of-mind and controversial issue in this context is the issue of consent. The survey that you referred to is an Australia-wide survey—

Ms Kirk: Yes.

THE ACTING CHAIR: that highlighted inadequate consent or lacking consent as quite a frequent flyer issue. In the hustle and bustle of a busy maternity service, how do you limit the lack of consent?

Ms Kirk: We are tripping into a really complex space. With the changes in how things have gone with professional indemnity and insurance, the practitioners have tripped into a space of defensive practice. In the defensive practice, intervention sits right up there. Consent starts with harm; what harms might happen. It is a complicated conversation between the practitioner and a client, a woman in this instance, a woman in the first instance. As things progress and the clinical situation escalates, as a woman escalates in labour, the capacity to have an in-depth conversation, as someone may be judged by later, gets more and more challenged.

In that situation, to have people understand each other, the very first thing you need is a relationship. When things are tense, the better your relationship is, the more quickly you can understand each other, and the more quickly you can come to a consensus with each other. Most women birthing in Australia today do not have a constant relationship and form a relationship with a single provider. They may have an obstetrician. With respect to the last evidence I looked at, the average wait was two

hours and the average visit was four minutes. That is not the basis of a relationship.

A known provider, from the beginning of your pregnancy to well after, creates a relationship so that in those times when the pressure is on, and the situation is escalating, you are already there. You have had a lot of conversations.

THE ACTING CHAIR: You may have already had a conversation about the possibilities.

Ms Kirk: That is right.

THE ACTING CHAIR: You can then say, “This is that thing that we talked about.”

Ms Kirk: That is right, and you have contracted beforehand: “In this situation, this is what it can look like. In that situation, my choices”—and I will talk through my lens as a midwife—“and my options as to what I can offer you are this, this and this. Then it would need to escalate to that and that”. And this is what they might be thinking of. You can have those conversations. But in today’s environment, the vast majority of women do not have the luxury of that relationship through the pregnancy so that, in those high-stress situations, they are already there, and the decisions can be consensual rather than an individual—

THE ACTING CHAIR: Going back to your submission, the stand-out thing for me was midwifery. I have to confess that I was old school. I had an obstetrician. I had five children and two obstetricians, one for the first lot, and I had great service. There was not much of a midwifery program at that stage. There is a big shift. It was certainly the case that I was aware that midwifery had a much bigger role to play in maternity services overseas than it did in Australia. We seem to be coming to that more slowly than other countries.

Ms Kirk: We probably have the world’s best educated midwives and we probably have the world’s—

THE ACTING CHAIR: The most under-utilised.

Ms Kirk: least utilised resource; as in, able to practise to its full scope of practice.

THE ACTING CHAIR: You pointed to some Scandinavian figures where 70 per cent of women had a midwife-led, one-on-one relationship, in programs like that. The figure gets as high as 80 per cent in New Zealand, I think. But in the ACT we are in single digits. How do we turn that around, and does that help to address, amongst other things, the issue of consent?

Ms Kirk: I will start with the second part, the consent, because a midwife, by definition, means with woman—therefore that concept of relationship and continuity of carer throughout your pregnancy. There is evidence that that does ameliorate that.

As far as the ACT goes, we are talking about structural reform. We are really talking about turning the whole system on its ear. I remember way back when they were redeveloping what was then Woden Valley Hospital to be the Canberra Hospital. I

remember way back then saying that what they were configuring as the birth centre should have been the delivery suite, and the rest of the hospital—as in the maternity unit—should have been the birth centre.

That was an opportunity, way back then, to turn it around and say, “Okay we’ll have a midwifery model of care; 85 per cent of women go through that and the 15 per cent that may trip into the”—

THE ACTING CHAIR: The tricky stuff.

Ms Kirk: “The tricky stuff belongs in a space that is appropriate for the tricky stuff.” Of course, we did not do it then and we have not done it in the next round. But that is what it would take. I know that there was a director way back who was very keen, in the redevelopment of the current Centenary hospital, to turn the whole place into a labour delivery recovery unit, have a midwifery model of care through the whole unit and have the smaller space for the other.

They were keen to do that then and they could not get it through. It will take charismatic leadership on the part of health policy planners, as well as the people who deliver the service, to see it happen for the ACT. That is what needs to happen. Do not get me wrong: obstetrics intervention when women need it is medicine at its best. It is beautiful medicine. It saves lives; it is the best medicine. But when it trips into a space where it does not belong, we are tripping into harm. It does not belong there, because that is what they do best. I am not critical of obstetrics; that is what they do best. Of course, they are going to do it wherever they can because that is what they do best. But that is not evidence-based care, and that does not produce the best outcomes for everybody. It is for a limited few.

THE ACTING CHAIR: It seems, from what I hear, that there is a political element or a patch element, and that people are pushing up against one another and rubbing each other up the wrong way, in a sense.

Ms Kirk: We would have to be naive to say that health is not a political space. It is a political space. I say “political”, meaning “power”. When it comes to health, health is no different from anywhere else. Of course, it does happen there. That is what makes me say—and I feel sad about it—that it is going to take charismatic leadership to have it differently. You are talking about turf. As far as I am concerned, I do not care about medicine and I do not care about midwifery. This is about the women. All we need to do is put women at the centre. Put a woman at the centre. With every decision we make, if it is not best for the woman, we cannot go there. That is all we need to do.

THE ACTING CHAIR: With your knowledge of the physical structure that we have at the major delivery points in the ACT, what needs to change in relation to infrastructure and the staffing to complement the charismatic leadership that needs to happen in order to turn—

Ms Kirk: As far as the space goes, the space is secondary, actually. It is about the people and the preparedness to practise differently. If there are policy and support, and an enabling working environment for people to work differently, it can happen anywhere.

There is an adage in Australia that we have tripped into. If there is a poor birth outcome and it happens at home, there is this adage that it is considered preventable, but if it happens in hospital it is considered inevitable. It is rubbish; it is absolute rubbish. There is no evidence to support this for a woman birthing at home. For the normal, healthy woman, her outcomes are all but identical to birthing in a facility. The facilities are actually secondary. What needs to come first is the will to have a different maternity service, a will to create an enabling environment for all practitioners in the maternity arena.

In Australia we are talking about midwives and obstetricians, largely. There needs to be a will to have an enabling and supportive environment for them. We can then turn around and say, “Okay, where is the best place for most people to birth, and where is the best place for most people to receive their care?” It does not all have to happen in a facility. Some of it does, and, for those who need it, as I said before, it is medicine at its best. It is beautiful care. That is when all practitioners in the space need to work collaboratively, to achieve the best health outcome for the woman and with the woman.

All the way through, there need to be enabling systems that allow the woman to have access to the care she needs at that moment in time. The problem with our system in Australia is that we need to say, “We’ll have midwifery-led care for the majority of women and we’ll have obstetric care for those others,” and allow the two to work in partnership, so that what is normal about a pregnancy can stay normal, and where she needs intervention, she gets intervention.

In our system there is this really crazy set-up around consultation and referral. If I were a midwife and I had my own practice, and I said, “I need to consult with an obstetric colleague,” in our system you have to refer. There is no remuneration for consultation but there is for referral. In our system, it is a matter of saying, “Okay, this is my patient”—

THE ACTING CHAIR: You are actually passing that patient on to somebody else?

Ms Kirk: Yes, rather than saying, “Okay, in this moment in time there needs to be some consultation; there may even need to be some treatment, but she can come to this space.” Coming back to that adage of the best care being at the level you require it at, as close to home as possible, acceptable, affordable and all of that, it is about allowing for that to happen. The system needs to have built into it the capacity to be dynamic, to allow the woman to move in it. Right now, that is not what we enjoy.

THE ACTING CHAIR: Is that a problem with the Medicare scheduling?

Ms Kirk: Yes, it is part of the Medicare scheduling. It is complex; it is a matrix of complexity that needs to be mapped through. We need to have a good look at that, and how we can best use the matrix that we have to achieve the best outcome for women in the ACT.

The very first thing is that there needs to be policy. There needs to be a policy of commitment to an enabling environment for all of the practitioners in the system; not

just some of them but all of them. With a bit of luck, and with good leadership, it should knock off some of the turf business that we have heard about.

THE ACTING CHAIR: Going back to the Medicare structure, is that an impediment to high proportions or a proportion of women having midwife-led care?

Ms Kirk: The Medicare system did change. There is a schedule now that midwives can claim against. They do not get remunerated equivalent to their obstetric colleagues for the same work, unlike in New Zealand. In New Zealand there is equivalence; not in Australia. There is not equivalence there. That would be more of an impediment at the availability of services end, because what is there to attract midwives to go out and practise in that way? The schedule does not provide them with equivalence. That is a problem with the schedule for midwives. For women, I am not sure. I do not think it is an impediment. For women, the impediment is about what the structure of the system does or does not provide. Even with a birth centre—with the home birthing program, I will not talk about how many women have gone or not gone through that, because access is so difficult—as we say, you almost need to ovulate, copulate and get on the phone, to get into the birth centre, let alone the homebirth. It is nigh on impossible.

THE ACTING CHAIR: Getting into the birth centre and being in that program are limited by what? The number of staff?

Ms Kirk: They are limited by the capacity of the service. We know that there are many more who want the service than can have it. As well, there is the risk profile as to who can go there and who cannot go there. It was originally designed for the most vulnerable, and for those people who struggle to feel comfortable in the regular system.

THE ACTING CHAIR: The medicalised system, yes.

Ms Kirk: Of course, it drifted away from that to being for the very well informed, the people with great capacity who could get in quickly. The most vulnerable were not the ones that could get in easily.

MS LE COUTEUR: Do you want to say more about homebirth options or, as you were saying, lack of options? Why is it so? It seems to be entirely reasonable, particularly if it is going to be a women-centred model of care. If that is what you want—

Ms Kirk: With the national maternity review, the one before last, I was on the advisory committee here. The committee were asked what they thought needed to be in the terms of reference. I said, “Let the terms of reference reflect the expectation around evidence-based care.” One of my obstetrics colleagues turned around and said, “What do you mean?” I said, “Since you’ve asked the question, I rest my case.” And I really meant it, because, for the well, healthy woman, there is no evidence to say that she should not be birthing at home if that is what she chooses, with a skilled birth attendant, which is a midwife.

There have been massive global studies done, and studies have been done here. There

have been studies done everywhere. There is no evidence as to why those women should not be supported, encouraged and enabled to have a homebirth. I think there has been a bias in the system for a very long time that has been overwhelming.

MS LE COUTEUR: Is that bias primarily around insurance issues? That is one of the things that has been—

Ms Kirk: The insurance situation did not help. That really saw a drop in the availability of midwives who did homebirths. That really took the bottom out of that market. I think that other biases are even stronger than the insurance one. We still have, nationally, the problem of homebirth midwives being unable to practise. They are able to practise but they cannot get insurance for the birthing, as in the birth itself, the intrapartum period, because there is no insurer that will cover them. The commonwealth provides subsidisation of insurance PI for obstetricians but it does not provide it for midwives.

MS LE COUTEUR: In New South Wales—I know of this because my daughter has recently given birth in New South Wales—the New South Wales department of health is providing the insurance there because homebirth was an option. She was a lot further away from hospital than anyone in the ACT is.

Ms Kirk: Yes, there are some programs where there is state coverage. Here we have a tiny one. They have done a pilot, but it is not out there for everybody. The insurance did take the bottom out of what was available, but even what was available was covering about one per cent of the birthing population. It is more than that; it is a public health thing. It is about homebirth being presented by policy and health services as a viable option; that this is a normal, healthy, viable option. For 85 per cent of women it should be considered as one of their first options.

MS LE COUTEUR: Do you have any idea of the cost to the government of one versus the other? Is there any logical reason for them to not encourage it?

Ms Kirk: No, the costs are not more. Even in this paper, we spoke about the British having done a study. They found that a normal vaginal birth is 30 per cent cheaper—saves the system 30 per cent—compared to a caesarean section. In Australia we are starting to creep up in the private system. We are up to 50 per cent. That is just bizarre. That is for the normal and the healthy, the very population that should be at home pushing their babies out in their own environment, with somebody that they know and somebody that will follow them through for some time after.

The other big issue that we have is the fractured nature of care. You go and see the practitioner, you go and have your baby, then afterwards you have to create new relationships again, right at a time in your life when you have run out of grunt to explain yourself to every new person that you come across.

THE ACTING CHAIR: Would the model of care be better if the person you met at your first obstetric appointment was not only the midwife who took you through to birth but also the MACH nurse?

Ms Kirk: There is a shared scope of practice between both. In Australia we chop

midwifery off far too soon, in my view. There is nothing magical that happens at two or six weeks after the birth. If you look at the international definition of the midwife, as adopted by the Nursing and Midwifery Board of Australia, as the foundation of the midwifery education programs, there is no reason why a midwife cannot be with a woman for a bit longer than that, if that is what the woman needs. Again it is about putting the woman in the middle rather than the professions in the middle.

You are right; and even the system that they are kicking in now here, of a woman during pregnancy meeting her MACH nurse, is a start. There does not need to be care going on throughout the pregnancy from both. Certainly, to know that this is who you are going to meet and who is going to work with you after that time has finished, can only be good. With respect to a woman knowing who her midwife is and who her obstetrician is throughout the pregnancy and after, the evidence is there.

THE ACTING CHAIR: Dwelling on that theme for a little longer, with the Scandinavian countries that have high participation and good outcomes, and New Zealand, which is closer to home, is there a continuity of care after birth from the midwife?

Ms Kirk: Yes, there is.

THE ACTING CHAIR: And how long does that—

Ms Kirk: In New Zealand I cannot tell you exactly. I think it is some weeks. That is a weakness. It can be better than that. We do not need to restrict it to a couple of weeks. Also, behind that there is some evidence that, for some women, it takes longer than that to establish breastfeeding. It takes longer than that to transition from having had a baby to the new world of, “Now I’m going to raise this child.”

THE ACTING CHAIR: Having a baby is the easy bit, often.

Ms Kirk: Yes, that is right. I think we should be really careful about restricting it to a few weeks because for some women that does not suit them, and that is not the experience globally. If you go to most countries, you will find that a midwife is part of a woman’s life for much longer than a few weeks.

If you look at the international definition of the midwife, it talks about the midwife being available to the woman. It talks about the newborn and the infant, and it talks about aspects of child care. Midwifery actually is much broader than this narrow focus on birth. It is about more than that, and it can be more than that, if it is enabled to be more than that, and if the systems and structures allow that to be the case.

At the same time there needs to be midwifery in partnership, because the moment comes when, for most women, they say, “We’re right now; we’re off.” You do not have to be with them throughout their lives. It is a matter of saying, “What works best for this woman? What might this woman need?”

By confining maternity or midwifery to that six weeks, we also lose track of those women, particularly, who trip into mental health issues. It has hidden the amount of maternal deaths in the first 12 months after the birth. The postpartum period needs to

be recognised beyond six weeks to at least the first 12 months to capture the true picture of what is going on for women. We play the first six weeks game, and we know, from a mental health perspective, that there are deaths in that time that have been hidden for many years that are attributed directly to the birth.

There are lots of reasons why I say we should be careful not to be trapped into only the first six weeks for a postpartum period.

THE ACTING CHAIR: The other thing that your submission raises is the hospitalised, medicalised model of care where someone presents, delivers and might spend a few hours a day or a couple of days in an antenatal ward and that there is no overlap of service between the delivering midwife and the caring midwife. It is not a criticism of those midwives; it is just the way the structure is. You work in a delivery suite, therefore you are not working on the antenatal ward. Those women in that situation, which is most women, do not have that continuity of care across from the delivery suite into the antenatal ward. Is that a common practice elsewhere?

Ms Kirk: It is a common practice in Australia. That was one of the reasons why, in the development of the current Centenary hospital, the director of the day during the planning process was very keen to see what we call an LDR model—labour, delivery, recovery—and even antenatally, if they need to come in beforehand. For the woman, the team should wrap around her rather than her having to interact with this team and that team. For the woman, it is incredibly stressful. Again it is about the service and not about the woman. And it can be done. There is really good evidence, and it is called an LDR model.

THE ACTING CHAIR: That can be done in a hospitalised environment?

Ms Kirk: Yes, it can be. You set your unit up in pods. The woman comes into that space, and that space is where everything happens for her. Even from an infection control perspective, it makes absolute sense. But with those spaces, for around every three rooms, there is a team allocated to that space. The woman only has to interact with that small team, rather than interacting antenatally with anyone that might wander into that ward. She then goes to the delivery suite and there could be any number of people there. If she stays for a bit longer, there will be any number there. It means that she only interacts with that team. It also means, for the team, that the team are skilled for the full suite of what the woman might require rather than their skills being particularly honed in one aspect but diminished in other aspects.

THE ACTING CHAIR: So you keep your skills up across the spectrum.

Ms Kirk: You keep your skills up and your skills are much broader—the whole team. There are lots of things about it that are really good. I would advocate that model for anyone who needs to birth in a facility. At the moment I think it is the best model.

THE ACTING CHAIR: Ms Kirk, thank you very much for Safe Motherhood's submission and for your presence here today, which was most informative. You will receive a proof copy of the *Hansard* transcript. If there is anything that you feel that needs to be clarified, you can take that up with the committee secretary. There were a couple of figures that you may have said you would check; I am not sure. If anything

comes up in the proof *Hansard* that needs to be provided, we will be in touch with you. Thank you very much for your submission and for your attendance here today.

WILLIAMS, MS MARCIA, Chief Executive Officer, Women’s Centre for Health Matters

THE ACTING CHAIR: We will now move on to the final witness today, from the Women’s Centre for Health Matters. I welcome Ms Marcia Williams. Thank you for appearing today and for the written submission that was provided to the inquiry. I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink-coloured privilege statement that is before you on the table. Could you confirm for the record that you understand the privilege implications of the statement?

Ms Williams: I understand them.

THE ACTING CHAIR: Thank you very much. Before we proceed to questions, would you like to make an opening statement?

Ms Williams: Yes. We were established in 1990. Access to maternity services has been one of the key things that I can see that we have been involved in all the way through. Way back in 1997 we had the original “having a baby in Canberra” pamphlet. Back in those days it was the place to go to, to find things out. We also ended up doing a whole range of information sessions with women and their partners. Times have changed. Women, back in the early and late 1990s, started to prefer to have access to information online. They were too busy to come to information sessions. Those sorts of things changed in the environment.

We also took up the issue of maternity services in 2003, for the last inquiry. It is interesting to look at the findings there, because some of the same issues are still relevant. I am sure you have seen it; we did the report on women in maternal care in the ACT, back in 2015. We really focused on the experiences of women, which is what I hope we can talk about today. A key point of that was 83.5 per cent of the women felt their experience was good, so a majority of women do have good experiences.

THE ACTING CHAIR: We do need to keep saying that.

MS LE COUTEUR: We do need to remember that, yes.

Ms Williams: Yes. It is bad if you have a bad experience, but the majority do have a good one. We launched in 2017 the Having a Baby in Canberra website. That was in direct response to, over the years, all the issues that we heard about women not being able to find the right information that was local and that told them what they needed to know about how to do things in the ACT. More recently, in late 2018, we worked with ACT Health to do some consultations with women about the model they are looking at now, the maternity access strategy, to touch base with them again about the important things in that regard. The same themes came up throughout those different consultations.

THE ACTING CHAIR: Would you like to, in 25 words or less, tell us what those same things are?

Ms Williams: Information provision is a key one. It is really hard to find information in this age online that is relevant and trusted. Particularly for GPs, so often these days they are not specialising in all of the areas that used to be the case. We found many times that the advice that GPs were giving women was not the right advice or that they contributed to some of the demand that happened in the Centenary hospital for women. We heard women telling us that GPs told them that they should go there because there was better care; also they would not be separated from their baby, whereas if they went elsewhere they would be separated from their baby if there was an issue. I think there was something about information for doctors and GPs.

There is a lack of understanding by women about models of care. All of our professionals talk about it, but in every consultation we have ever done, women do not understand them, unless they have relied on friends who could talk them through it, and who had been through the process.

Continuity of care comes up every time—the need for that continuity of care all the way through and for as long as is needed. Postnatal supports are also an issue, particularly as women are getting out of hospital earlier these days. Another is breastfeeding, as well as mental health supports and access to those.

I heard Mary Kirk talking before about midwifery. Having that afterwards, for as long as you need, was a key one. Within the maternity system, women want to be listened to and included in the conversations. They want to have their questions answered. Even if it is not at the point where decisions are made, they want the decisions to be explained about adverse incidents or changes to the way they thought things were going. They are probably the key things that come up every time.

THE ACTING CHAIR: Ms Kirk, the previous witness, spoke at length about continuity of care. You heard most of her evidence. Is there anything that you want to add in that space?

Ms Williams: No, just to reinforce it. For us, we heard from women on the mental health side of things, the access. If you have left the hospital earlier than you would have otherwise and you are having troubles with breastfeeding, those mental health issues or support for postnatal depression are really important, and we are just not keeping up with the demand for that. Some of that is because that support is not offered up front, and kept going for as long as people need. I would just reinforce that.

THE ACTING CHAIR: Are you aware of whether there is research that might indicate this? Something that has really struck me this morning is that, if you do not have that continuity of care or if you do not have good follow-up, people are more likely to have the wheels fall off.

Ms Williams: Yes. We talk about the experiences of women, but I know, from dealing with some of the maternity services and PANDSI, for example, that there is research that shows that investment in that actually reduces that—

THE ACTING CHAIR: It is probably something we need to look at.

Ms Williams: I could follow it up for you and come back to you.

THE ACTING CHAIR: If you could point us in the direction of appropriate research, that would be helpful. We might follow that up with PANDSI as well.

MS LE COUTEUR: One of the comments that was made by Women with Disabilities was that many of their community suffer from disadvantage—poverty, social isolation—and that this is one of the contributing factors. Clearly, non-disabled women also suffer from these issues. Do you find it is an issue in terms of maternity and birthing services, and the experience?

Ms Williams: I know this from working with WWDACT, Women with Disabilities ACT, and with other groups. We are doing a consultation with LGBQ women, and it came up in that around discrimination or access to services that were not sensitive to their needs. I think there is this mainstream service that is provided and often they do not think about how it is adapted. Are you talking particularly about—

MS LE COUTEUR: Mainstream women can still be poor.

Ms Williams: Yes.

MS LE COUTEUR: They can have other forms of disadvantage, apart from disability or sexuality. Is this an issue for the mainstream?

Ms Williams: I think it is about access to services, like being able to get to services, to be able to afford those services. Women are finding it very hard. If you cannot get supports that are given by GPs because you cannot access bulk-billing GPs, that is an issue for women, including in the maternity space. We do not have data on women with disabilities because it was more general.

MS LE COUTEUR: I said that as an introduction because people in that community—

Ms Williams: I think it is harder for women who are on low incomes or who are experiencing disadvantage to actually do things in the medical system more widely at the moment, and to access those easily.

MS LE COUTEUR: Absolutely. There are not even enough GPs. With respect to accessing the services through the hospital, are there any barriers to that?

Ms Williams: Not off the top of my head. I do not think we covered that. I would assume that that would create some barriers about getting there and being able to access it. Sometimes that environment creates barriers for women in low income areas as well. That is not in the research that we have done, but ours was a broad one. We are going to do this research again, probably into early next year, to look at the changes in the system, to compare them and see if there have been improvements. We may be able to pick up some of those in that as well.

THE ACTING CHAIR: Your submission deals with what women have said about their experiences. That is extraordinarily useful to us because it puts in one place the

experiences of a lot of women. One of the things that we touched on is that high proportions of women—80 to 85 per cent of women—have a good experience.

Ms Williams: Yes.

THE ACTING CHAIR: Are there things in that space where we could make it better or should we be concentrating on the other 15 per cent?

Ms Williams: A bit of both, I think. Some of the ways we are heading with the new changes to the maternity system are what very clearly came out for women: having locally based access to information and advice early before you become pregnant, during the pregnancy, and not always having to be part of the hospital system. We heard very strongly in the consultations that, “We’ve got these locations, we’re going to our doctors locally, we’re going to the family and child health centres; why aren’t local information and those supports available in those?” That was a very strong feature around how you could support better access for everybody.

The other bit that women talked about in terms of the percentage that did not have a good experience, was that much of the way the information is presented to women early in the piece is about the ideal birth and the ideal pregnancy. For women who do not have an ideal experience, none of that is ever discussed or presented. You go along to the films with your partner and look at a normal birth, so if you encounter a not-normal birth or pregnancy, it is more traumatising, anyway. I think there is still a need to focus on that front end.

THE ACTING CHAIR: Is there a high sense that if you do not have a normal birth, you have in some sense been a bit of a failure?

Ms Williams: It depends on the treatment that you are provided in the hospital and how people provide that information to you, or deal with you. One of the things that women told us, in that 15 per cent who had had a bad experience, was that it was not so much the experience; it was about when something changed, and decisions were made that were different from what had been expected. When there was an emergency or something that needed to be done straightaway, with the women who fared better in that area and still found it a positive experience, it was about the way it was handled. It was about, as soon as possible afterwards, having a conversation, and debriefing them about what had happened and why, so that they did not feel it was something that they had done.

THE ACTING CHAIR: “I’m a terrible mother.”

Ms Williams: Yes, exactly; or, “It’s only me this has happened to.” When they sat down with them and went through it, it enabled them to work through the whole process. If that did not happen, they were more likely to have that unsatisfactory experience and the trauma that comes from that, and that often led to that postnatal depression, and not feeling that it had all been done well.

MS LE COUTEUR: You talked about people liking things being close to home. I think you had three home birthers in your survey. Do you believe that there is an unmet demand for home birthing?

Ms Williams: Yes, we hear that all the time. Although we did not have high numbers in a lot of the consultations we had, in the forums that we have with women homebirth is often raised. We have never done a survey that asked who would use it, if it were available, but I am sure a lot of women would take up that option if it were available. The medicalised model works for some, and first-time mothers sometimes want that. There are others who would much prefer that.

MS LE COUTEUR: I would be really interested if you had an idea of the unmet demand—

Ms Williams: We do anecdotally, yes.

MS LE COUTEUR: which I assume is fairly huge.

Ms Williams: I would assume so, too. We were part of, with HCCA and others, the original discussion around the trial. Back then I remember hearing about data that showed there would be high demand for it. But there was a need to go slowly on a trial, to make sure that it was safe.

THE ACTING CHAIR: You said that everything that needed to be said about continuity of care was said by the previous witness. It seems to be such an important issue. In your research and in the place that you sit, in the Women's Centre for Health Matters, how important or how life changing would it be if the CaTCH nurse and the MACH nurse were the same person?

Ms Williams: Women told us that where they had a relationship with someone and that was continued, it made the whole experience better for them. Women talked a lot around having to explain their situation over and over again. When you are in the middle of giving birth, or after birth, when things are going wrong, having to explain all of your history and what had happened to you, what came up quite a few times was about if they had only known that information. In terms of being able to have the same person throughout, or as closely as possible, or handovers between a team of people—

THE ACTING CHAIR: Better handovers.

Ms Williams: Yes, better handovers and a constant team of people; that came up frequently as being a better experience for them. Particularly with the MACH nurses, they came up often in our discussions with women. Suddenly, you are seeing someone that you have not talked to before, who does not know the circumstances and has not had that relationship with you. If that did not work, it was really bad.

THE ACTING CHAIR: It is quite a different relationship. Sometimes you are still in your pyjamas and—

Ms Williams: You have not been out of the house for weeks.

THE ACTING CHAIR: a relative stranger walks—it could be a complete stranger on the first visit, or a relative stranger—through your front door. It can be quite

confronting.

Ms Williams: And quite damaging as well, if it is not a good interaction.

THE ACTING CHAIR: Yes. If you had a relationship—

Ms Williams: Beforehand.

THE ACTING CHAIR: beforehand, there must be a sense that you have to get up and tidy the house, have a shower, put your make-up on and look normal and together. We know that that is not the case—

Ms Williams: No.

THE ACTING CHAIR: but if you open the door in your pyjamas, you are going to feel judged.

Ms Williams: Yes.

THE ACTING CHAIR: Even if you are not being judged, it would be good to be able to avoid that, by having that relationship established beforehand.

Ms Williams: It does not necessarily have to be the same people. I realise that that is quite cost intensive. There should be the connections with people beforehand, so that you know who you are going to be linking to, and be able to have that first conversation before you leave hospital. This is someone you already know and like and they have already understood what has happened to you, rather than finding out when they turn up on the doorstep.

With many of the experiences that women had with MACH nurses, it was about them not understanding the circumstances they had been through and dismissing their concerns or fears. It made that whole experience worse. Actually being able to connect with that experience in the hospital, know what had happened, do the handover and continue on will be a better experience, anyway, whether or not it is linked fully all the way through. Any interaction beforehand will improve it.

THE ACTING CHAIR: The previous witness talked about a team approach. You have just described a team approach. Are you aware of gold standards in that regard?

Ms Williams: No. Again I am happy to take a look. I know Ms Kirk also said that in the recent maternity strategy at a national level, a lot of those things were flagged. We could have a look.

THE ACTING CHAIR: We can probably do that as well.

Ms Williams: I will take a look and see.

THE ACTING CHAIR: Thank you very much for your attendance here today. I thank the Women's Centre for Health Matters for their extensive submission and insights. You will receive a draft *Hansard* transcript from the committee secretary. If

there are issues that need clarification, you can take them up with the committee secretary. Thank you for your attendance here today and for your participation in the inquiry.

Ms Williams: Thank you.

The committee adjourned at 12.27 pm.