

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

### Inquiry into perinatal services

Melbourne — 16 October 2017

#### Members

Mr Paul Edbrooke — Chair

Ms Cindy McLeish — Deputy Chair

Ms Roma Britnell

Dr Rachel Carling-Jenkins

Ms Chris Couzens

Ms Maree Edwards

Mr Bernie Finn

#### Witness

Ms Rebecca Bartlett, nurse and midwife, mAdapt project.

**The CHAIR** — I welcome to these public hearings Ms Rebecca Bartlett, a nurse and midwife from the mAdapt project. Thank you for attending here today. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. These proceedings will be recorded, and you will be sent a proof copy of the transcript. Thank you so much for coming in today. I now invite you to make a short presentation, and we will follow up with some questions.

**Ms BARTLETT** — mAdapt wishes to acknowledge the traditional owners of the land on which we meet today, the Wurundjeri people of the Kulin nation, and I pay my respects to their elders, past, present and emerging.

I founded mAdapt in mid-2015 in response to the lack of evidence-based digital health interventions focused on sexual and reproductive health available to communities on the move. At mAdapt we work with these communities to develop simple yet innovative solutions to the problems faced in accessing respectful, quality reproductive health services.

### **Visual presentation.**

**Ms BARTLETT** — Today on behalf of mAdapt I will speak to the first, sixth and seventh terms of reference listed pertaining to the inquiry and offer recommendations at the end. I have worked in the sexual and reproductive health sector since 2004. I am an experienced registered nurse and midwife and global health researcher. I have designed and led community-based programs, both in Australia and overseas, and further to this I have practised throughout rural and remote settings in Australia, the US, Papua New Guinea and the Philippines, as well as in both the private and public sectors of the ACT, New South Wales and here in Victoria.

Over the past 13 years I have had the privilege to support women and their families through the perinatal continuum, through the joyful and celebratory times but also through the expected and sometimes unexpected deaths of their babies, through coming to terms with the genetic disability of their newborn and sometimes an acquired disability of their own as a result of the pregnancy and birthing process. I have been present for women when they have had literally dozens of family members at the door trying to enter the room as soon as they hear the first cry, and I have been present for women who have told no-one they are pregnant and who have had to walk themselves to hospital in labour and return home a few days later with their baby, completely alone.

What all of these women have in common is not their vulnerability during this often precarious and emotional time, because many of them do not feel vulnerable, nor is it their sense of strength and power, because again many women do not identify this as a time during which they felt particularly strong or powerful. Rather, what all these women have in common is the desire and indeed the intense need to feel safe, welcomed and respected, to feel seen, to feel heard and, most importantly, to not feel alone. This is true irrespective of the woman's age, sexuality or gender identity, her education or her upbringing, and it is true regardless of her religion, her cultural background or her language. This has been supported in the literature countless times and yet rarely has it been acted upon at a systematic level in any of the countries in which I have worked.

In Victoria about 80 000 women give birth every year, and in 2015 this included 2 per cent of women who identified as Aboriginal and Torres Strait Islander, 1.6 per cent of women under the age of 20, and 30 per cent of women from non-English speaking backgrounds. This past August, in Northern Hospital alone, one baby was born every 90 minutes. Northern Health encompasses three of the fastest growing suburbs in Australia, and the hospital services over 130 nationalities, including the majority of the humanitarian arrivals who have settled in Melbourne over the past three to five years.

Whilst metropolitan Melbourne oversees the vast majority of these non-English speaking women during their perinatal journey, regional Victoria averages about 10 to 15 per cent of overall humanitarian arrival intake, yet it is within these regional areas that mothers fare the worst. Loddon, Hindmarsh, Yarriambiack, the Pyrenees and Central Goldfields round out the top 10 LGAs with the worst outcomes for mothers.

Women who do not speak or read English as a first or subsequent language, as well as those who do not read in their own language, or any language for that matter, are at a systematic disadvantage in accessing both information and services that relate to pregnancy, childbirth and family planning methods, including general, sexual and reproductive health. This not only violates their fundamental human right to quality, accessible and

safe health care, it ultimately places an undue burden on both the local and national health systems within Australia. Despite this there is a noted absence of quality, evidence-based, easy-to-understand information relating to maternal health services in Victoria and Australia at large for women from culturally and linguistically diverse backgrounds, and this is even more true in the regional areas.

Within Victoria the current health promotion websites for non-English-speaking communities require you to navigate three screens in English before you can find the relevant material in your native language. You also need to be able to know how your language is spelt in English, or at least how the letters look, and you need to be able to decipher the overly medical and clinical documents, few of which offer visual learning opportunities for low-literate users and almost none of which offer anything but token efforts towards cultural relevance. These websites are helpful, but they have been designed for the health professional to locate and decide which information is relevant for the health seeker. This once again takes away the agency of the women within their care and prevents them from becoming autonomous decision-makers over their own care pathway and, ultimately, their own body. This also increases their chance of experiencing an adverse outcome as a direct result of their pregnancy or birth.

A report last year by the Multicultural Centre for Women's Health noted the following. Mothers born overseas were more likely to have instrumental vaginal birth or caesarean sections compared to Australian-born women. Both first-time mothers and mothers who had previously given birth in east African countries had elevated odds of unplanned caesarean labour. South Asian-born women were more than twice as likely to have a late-term pregnancy stillbirth than other Australian-born or south-east Asian born women. Lebanese-born women had the highest rate of stillbirth compared to the low-risk women in Australia and other women born overseas. Women born in east African countries experienced increased perinatal deaths and other adverse perinatal outcomes compared with Australian-born women, and women from Eritrean Sudan are particularly at increased risk of adverse outcomes.

**The CHAIR** — Rebeccah, just around that, what is the reference for those stats?

**Ms BARTLETT** — Where did I get them from? The Multicultural Centre for Women's Health's *Sexual and Reproductive Health Data Report*. Further to this, the intersectionality of women within Victoria's maternal health system cannot be overlooked. Indigenous women are overrepresented in the justice system, accounting for 34 per cent of the female prison population, despite making up only 2.2 per cent of Australia's overall female population. Ninety per cent of women who live with an intellectual disability will experience sexual abuse at some point in their life, which may result in an unplanned and unwanted pregnancy as well as a non-consensual termination of pregnancy.

The low-paying sex work industry is saturated with women from non-English speaking backgrounds, many of whom have been trafficked here and are completely inaccessible to the health and support services that could offer medical care and safety. A recent study from the Australian Institute of Criminology estimates up to 70 per cent of the 22 000-plus sex workers in Australia were born overseas, yet their inaccessibility means little meaningful data exists to represent their need. Almost all of these women will experience violence at some point in their life, and based on existing statistics for first-time mothers in Australia, one in four will experience violence from a partner during pregnancy and one in three before their child turns four.

How does all this relate to the care of women experiencing the Victorian maternal healthcare system? Many women from non-English speaking backgrounds are routinely sidelined from their own decision-making when a healthcare professional decides interpreters are only needed for important conversations. In one study across Victorian emergency departments it was found that only one in every 86 patients with low-level English was connected with an interpreter. Another study averaged 1.6 per cent of usage across some general practices. This may seem surprising, yet this past August I had to advocate for a woman to have a phone interpreter at the very time a set of forceps were being placed on her baby's head because the doctor did not think her lack of English warranted one sooner. No conversation was had with this woman after the birth, of her instrumental delivery, her extended episiotomy or why her baby was now in NICU.

When I visited her two days later on the postnatal ward no staff had made any attempt to contact the phone interpreter because one had already been booked for day four to speak with the NICU staff, and that was deemed enough. Staff informed me the mother was non-compliant with care and that she was not bonding with her baby. I immediately called the TIS phone interpreter and the three of us spoke for almost 40 minutes about her postnatal care, her emotional state and the tests her baby had undergone that she was becoming increasingly

anxious about. The mother explained to me that she had become incredibly distressed about her baby, but she did not know how to ask for care or if she was even allowed to.

Despite the 24-hour availability of interpreters by phone there is an overreliance on family members, including children, to translate for the women we care for. This is not only inappropriate; it actually violates our duty of care in many instances where we are expected to responsibly and discreetly ascertain risks of family violence and mental health concerns using potential perpetrators or survivors as translators.

When staff are not held accountable for ensuring accurate and effective communication between themselves and the women within their care, when we do not protect the woman's right to informed consent in a language she understands, we not only fail in our duty of care but we perpetuate an environment that says, 'This woman's rights only matter if she speaks our language and if she is willing to speak up'.

For many of the women I have spoken to, having an interpreter or a bicultural birth support during labour who can offer explanations and comfort is more important than having access to an anaesthetist who can offer an epidural. Many of the women from our at-risk communities mentioned earlier experience a systematic community-wide distrust of government institutions, and this extends to hospitals and healthcare system as a whole. For some it relates to torture and trauma experienced within medical facilities in their home country or in detention offshore. For many Indigenous women intergenerational trauma is an ever-present ghost threatening abuse, assimilation and childhood removal from kin and country by the state. What this translates to are significant groups of women who refrain from accessing healthcare services altogether and who rely on community information sharing.

This information is often inaccurate and sometimes dangerous, and it adversely affects the health outcomes for the women for whom it is directed. So taking all of this into account, where does this leave us? I have deliberately used the majority of my time during this session to lay out the problem as I see it. My findings have been validated by countless other health professionals, program workers, policy officers and funders within both refugee health and maternal health and the small number of providers who intersect both.

More importantly my findings have been validated by the women and the communities with whom mAdapt works. Together we have co-created Shifra, a web app that supports refugee and new migrant communities, increasing their access to reproductive health information and services within Victoria. Specifically Shifra increases accessible, culturally sensitive sexual and reproductive health information in the user's language of choice, including highly visual content for low-literate populations. Shifra connects users to accessible healthcare services that specialise in refugee and migrant health. Finally, Shifra maps user searches, illuminating unseen and unmet need by the geographic regions, thereby helping us work with LGA partners to effect meaningful service and policy change and reduce resource wastage at the local level.

Shifra and the work of mAdapt are helping to bridge the gap of quality healthcare access for some of Melbourne's most at-risk communities. However, it is not an elixir. Systematic and sustainable changes to accessing health need to be made in an authentic and community co-designed way. Like most public health and prevention-based interventions the benefits may not be seen immediately. However, the following recommendations will improve the quality of care and health outcomes the state of Victoria offers to women within the maternity system.

**Recommendation 1:** a standardisation of respectful maternity care and accountability for the same. We must hold all healthcare workers accountable for delivering respectful maternity care, which includes explaining all health interventions to women and their families in the language they understand. This should occur, where possible, before the intervention takes place and include structured debriefing with every woman following any procedures that deviate outside the standard of normal maternity care.

**Recommendation 2:** increase accountability for communicating effectively with CALD communities. All interventions for the community need to be designed with the community and not a single representative speaking on their behalf. Teams should be multidisciplinary and the co-design effort needs an equity-based approach which includes funding for monitoring and evaluation as well as compensation for the community members who attend on their own time. Questioning who is at the table and, more importantly, who is not is essential to the authenticity and acceptance of any project. These co-design sessions not only help to recognise the unique knowledge communities have around what problems they are facing and what solutions will work

for them; it is also a way to develop the capacity of members who can and should be the future health leaders of tomorrow.

Recommendation 3: support for the CALD women to navigate the system. In preparing for this inquiry I reached out to contacts at the Northern Hospital transcultural and interpreting service and the Multicultural Centre for Women's Health. Both voiced active support and suggested the following initiatives: investing in video interpreting; strengthening in-house accessibility, hospital-based translating and interpreting services from 8.00 a.m. to 8.00 p.m.; increasing female interpreters, especially those with knowledge in sexual and reproductive health and those from emerging languages including Karen, Hazaragi, Persian — both Dari and Farsi — and Dinka; trained bicultural workers, particularly those who work in hard to reach areas, including regional and rural areas as well as women in prison; and auditing of consent for non-English speaking patients.

Recommendation 4: a focus on meaningful data collection related to marginalised communities. All people have the right to be represented in the data. However, many women, especially those from non-English speaking backgrounds, remain invisible to the systems that govern them. Last year the spatial analysis of humanitarian arrivals report outlined the number of areas in which our data collection within Victoria could be made more complete and representative of these communities. I suggest reviewing the summary report or at least the list of 12 recommendations they offer for future policy and practice, and I have printed those out today.

Whilst I did not speak to the following two groups specifically, it is important to note that between five and 15 children live with their mothers in prison in Victoria at any one time and over 2 million Australian women live with disability. These two at-risk communities have very little data available specific to their maternal health or welfare experiences.

Finally, maternal health does not exist in a vacuum. Education around family planning and birth spacing must not be deferred until after the baby is born. Further to this, a more honest and frankly more courageous effort must be made to discuss sensitive issues around safer sex, sexuality and gender-based violence in schools. We know that teenagers are actively exposed to an overly sexualised representation of self through social media. We cannot completely safeguard them from all of this, but we can arm them with the knowledge of how to prevent STIs and unplanned pregnancies and how to negotiate consent. There is ample evidence to suggest that this should take place well before their teen years and that this will reduce the number of adolescent pregnancies.

This list is extensive, but supporting innovations like mAdapt, which addresses many of the issues listed above, and all four recommendations is one place to start. mAdapt should be made available to all mothers throughout Victoria as it provides a measurable way to improve access to sensitive yet necessary health promotion topics for women from both English and non-English speaking backgrounds.

Melbourne is considered the most livable city in the world repeatedly. Indeed I moved here this time last year because of the diversity and social inclusiveness it represents to the outside world. If we are to take pride in the hundreds of nationalities we have created a home for here, we need to support these communities to integrate and not assimilate. Their cultures and differences are what makes us creative and innovative as a city and a community. When we welcome them in word only and not action, we create barriers and divisions that allow these women and their families to fall into the gaps. This does not just affect them as individuals worthy of equal and equitable access to health care before the law; it places an undue burden on the healthcare system as they will eventually present to our maternity services sicker and more dependent upon higher acuity care.

When information is not accessible, it might as well not exist. In the words of childbirth author and journalist Diana Korte, 'If you don't know your options, you don't have any'. Health professionals like myself are the gatekeepers to knowledge within the maternity and reproductive health sectors. We need to be supported to loosen our grip on the keys, and mAdapt is doing just that. I would like to thank the committee for its time and welcome questions and comments.

**The CHAIR** — Thanks, Rebeccah. Are we able to get a copy of the presentation as well?

**Ms BARTLETT** — Yes.

**The CHAIR** — Thank you for your contribution. Just one really quick question from me. I was really surprised to hear that one in 86 patients are connected with an interpreter. That sounds just like a recipe for disaster.

**Ms BARTLETT** — It is not an average, but that is one study, yes.

**The CHAIR** — It is quite high. It is remarkable. In your opinion is that because there is no policy in those health services that requires interpreters, or is it people not following their policy?

**Ms BARTLETT** — I think it is a combination. I think the time crunch that people are under makes it easier to presume the patient or the woman in your care understands what you are saying, and women, both non-English speaking and otherwise, have been trained to nod their head and say yes when you ask, ‘Do you understand?’. I think that there is no accountability for getting them an interpreter. However well-meaning practitioners are — and I include myself in this — there are often times when we like to believe that they understand more than they do.

**Ms EDWARDS** — Thanks, Rebeccah. More broadly, can you perhaps talk to what sort of training midwives receive in relation to women from CALD backgrounds during the course of training to be a midwife? In relation to the workforce and the workforce capacity — and clearly we have a shortage of midwives — are you aware of any particular schemes that exist or programs that exist to encourage women from CALD backgrounds to train as midwives?

**Ms BARTLETT** — To answer your first question, I trained at UTS in Sydney. I did my nursing training at the University of Sydney. I can remember one class in my nursing degree that was focused on Aboriginal and Torres Strait Islanders. I do not remember any on non-English speaking women, and I do not remember anything in my UTS training. Being fair, it was many years ago. It could be different in schools that are more in the western suburbs, for example. I think there is a lot of expectation that you will get on-the-job training, and my first two years out I worked in a predominantly white, Anglo hospital. The demographic was, I think, pretty non-diverse. It is just that this is my passion, so I have taken it upon myself to do a lot of this research, but I do not think there is an active attempt to encourage.

As far as recruiting women from bicultural, bilingual backgrounds, I think that you would have to ask the ANMF and the schools. I think working with Birth for Humankind we have a lot of student nurses — and we have some in the room today — and student midwives who come through our service, and a lot of them are from bicultural backgrounds. Whether they have been actively recruited I am not sure, but I would like to see that, particularly for the women who have experience in their home countries as midwives who might not be able to become a midwife here for financial issues or family, because they do not have time to take away from their family. Having them recognised as a women’s health bicultural worker is really important.

**Ms EDWARDS** — Just a question around the funding for mAdapt. How did you secure funding?

**Ms BARTLETT** — Most of it has been my own. I have invested close to \$20 000 of my own money into that, and that is not including the hours I put into it, which is more than 40 hours a week. We have had a small grant from North Western Melbourne Primary Health Network and a small grant from a Rotary club in Beaumaris, and the rest has been in-kind donations.

**Ms McLEISH** — Thank you, Rebeccah. How long has mAdapt been running?

**Ms BARTLETT** — Two years. Well, we launched in August our prototype, but as an organisation —

**Ms McLEISH** — August this year?

**Ms BARTLETT** — Yes. When you do not have money and you are not a tech person, it takes about two years to create an app.

**Dr CARLING-JENKINS** — I think that is doing well, actually.

**Ms BARTLETT** — Yes, I am pretty happy with that.

**The CHAIR** — We are going to get some tips off you, are we?

**Ms McLEISH** — My next line of questioning actually is a little bit IT-focused, because you talked about the difficulty in finding language-appropriate information. You gave an example, I think, of having to look through three screens before you find the right information.

**Ms BARTLETT** — Yes, that is the health translations Victorian website.

**Ms McLEISH** — How would you do it?

**Ms BARTLETT** — How would I do it right now as an English speaker? I would go to —

**Ms McLEISH** — Because you cannot have every language on the home page.

**Ms BARTLETT** — Do you mean how we would do it as mAdapt?

**Ms McLEISH** — No, I mean how would you fix the system?

**Ms BARTLETT** — Okay. I think first and foremost we need to create interfaces where you do not have to navigate English to get to the language you want. I have had countless interpreters tell me that a lot of what we offer is Google-translated documents, or documents that do not quite meet the nuanced aspects. So I think we need to work with the communities, particularly the bicultural women's health workers and the Multicultural Centre for Women's Health, which is working with me on this, to find out what are the key areas that, in this case, women want information in, and we have done that; to create the interface so that she is not required to go through an English-speaking or English-reading app; and also to make sure that if she does not read, there is a lot of video and visual, comic-based content. In fact you can do this with mAdapt at the moment: if you open up your phone and you speak Arabic, it will immediately take you to the Arabic-translated content on that site rather than expecting —

**Ms McLEISH** — How does that happen?

**Ms BARTLETT** — How does that happen — as in?

**Ms McLEISH** — How do they get to know about that app?

**Ms BARTLETT** — At the moment we are doing word-of-mouth and train-the-trainers, so I have had a \$500 grant to work with —

**Ms McLEISH** — And let us look beyond you, at the system. We are looking statewide.

**Ms BARTLETT** — I think first and foremost people need to be able to access this information in and of themselves. They should not have to be reliant upon a nurse or a doctor to give them the resources, so you need to give it to them on their phone, because that is where they are accessing it. They are accessing it —

**Ms McLEISH** — So who does that? Who fixes that?

**Ms BARTLETT** — Maternal and child health nurses are the first place to start, midwives. The same way we give them —

**Ms McLEISH** — So you would have one in every language?

**Ms BARTLETT** — Eventually that is the goal, but at least in the top five languages — well, the top seven, so the five emerging languages plus Chinese and Vietnamese.

**Ms McLEISH** — So help prior to engaging with maternal and child health, which happens post-delivery?

**Ms BARTLETT** — Yes, but also working with midwives through antenatal —

**Ms McLEISH** — So who would give it to them before? If you do not have a midwife, how do you do it?

**Ms BARTLETT** — Community health workers. A lot of the women, for example, when we go to some of the housing developments on Hoddle Street, are not pregnant yet but they come to women's health and maternal health, navigating the maternal health system education classes, so we are working with that particular

neighbourhood house to work with 20 of their women to do a train-the-trainer, so each woman learns how to use the app, learns what the content is, tells us what they think, how it could be improved —

**Ms McLEISH** — That is your app.

**Ms BARTLETT** — That is what we are doing at the moment, and then they share it word-of-mouth.

**Ms McLEISH** — Yes, but that is about your app.

**Ms BARTLETT** — That is right, but that model can be done with anything essentially. If you can create it in a digital interface, not only are you getting it to people in a discreet manner, you are also measuring that they are getting it. You are able to say not just that 20 people turned up to a thing but that 20 people are using it every day.

**Ms McLEISH** — So with some of the more vulnerable people of CALD backgrounds, for example, is it easy to get those who are pregnant along to those —

**Ms BARTLETT** — It entirely depends upon the community. The Karen community is a lot harder to access in some instances around pregnancy as opposed to some of the Somali or Eritrean communities. You have got to look at whether or not they are recent — that they have been settled for five to seven years or whether they are ‘fresh off the boat’. For example, the Arabic-speaking community has the highest rates of also being English-speaking at some level. They are a lot easier to engage with than the Hazari community, for example, or the Dari community — it just depends. That also depends on geographic region, if they are more established in Dandenong and Casey as opposed to Sunshine and Werribee. You really have to work with that particular community, and that is why I think having one representative to talk about the 615 000 people in Victoria who have low-level English is not effective. You need to work with the communities, and that is where the local government areas come in.

**Ms McLEISH** — Do the communities ever look for the department of health’s website?

**Ms BARTLETT** — They do. I think the Better Health Channel, Health Translations and the women’s section all have fairly helpful resources for the non-English speaking, but again —

**Ms McLEISH** — You have to get to the English one first?

**Ms BARTLETT** — Better Health has a dual thing, so you can look at it and it has got English on one side and the native language on the other, but you still need to navigate in English to get to that page. Does that make sense?

**Ms McLEISH** — Yes, it does. I am still trying to work out the system so that you do not have to navigate in English to get to the page.

**Ms BARTLETT** — It has not been done yet. I promise, I have tried and tried. I did not want to create a start-up myself; I wanted to work for someone else. It is just not there.

**Dr CARLING-JENKINS** — I will just ask one very, very quick question, Chair, if that is okay. Thank you for coming in, Rebecca. The mAdapt program has been running for two and a half months in the pilot phase, is that right?

**Ms BARTLETT** — Yes.

**Dr CARLING-JENKINS** — What has your initial feedback been?

**Ms BARTLETT** — The interface itself is very accessible and people were liking that. The content is quite clinical still and that was no surprise because we had a bunch of nurses and midwives putting content in, and that is what we deliberately did. We wanted to create placeholders for content and then send it out and say, ‘Is this what you want?’. Overall the feedback has been, ‘Yes, this is what we want. We just need it to be simpler’, and we need more videos, we need more graphic content. The only area we missed out on initially was sex work, and I was reached out to by RhED, and they are now working on the sex-work content with us.

**Dr CARLING-JENKINS** — Okay. Fantastic, thank you.



**The CHAIR** — Thanks, Rebeccah. So I can get onto mAdapt’s app pretty much right now on any device?

**Ms BARTLETT** — It is Shifra.io — mAdapt is the company and the website is Shifra.io.

**The CHAIR** — Thank you for giving us your time today. Sorry we are under a bit of time constraint.

**Ms BARTLETT** — It was a long speech. I took my moment.

**The CHAIR** — You were very informative though, but we get a lot of people in here and they have got so much information to get across to us. You did it quite well. Thank you so much.

**Ms BARTLETT** — A pleasure. Thank you.

**Witness withdrew.**