Transcript – Pregnancy and deafness

Meghan:

Hello and thank you for listening to this podcast.

My name is Meghan Luton, I am midwife and a midwifery lecturer at Middlesex university. I am currently doing a PhD exploring the experiences of deaf women in maternity care and I would like to share with you some of the communication barriers deaf women and their families may face while trying to access maternity services.

I will try and give some solutions, but the list is not exhaustive, and I encourage you to think outside of the box but more importantly listen to the women in your care. They have been navigating the hearing world for a long time and are the experts in their own needs.

When I say deaf in this podcast I am referring to deaf, deafened and hard-of-hearing women, unless I specify differently.

I'm going to start with primary care or outpatient services. For example, Antenatal Clinic.

How do women book appointments or change appointments?

If the only option is for women to call the service then this is not accessible. Deaf women should be given an email address or mobile phone number that they can text. Where possible, they should have continuity of care from their antenatal midwife to avoid missed messages.

For women who require a BSL interpreter, this can take a long time to arrange, depending on your trust policy. Women will put this information on their self referral form and booking clerks should be aware of how to book interpreters so that this can be done at the same time as arranging the appointment.

During COVID, many Antenatal bookings have moved to phone bookings. It is worth knowing how you will provide the same care to deaf women. If they use BSL, many interpreting services will provide support via Zoom or other online video chat services. However, if they do not use BSL and rely on lip reading, how will you provide this?

For women coming to clinics, how do you call them to the room?

If your current practice is to go out and call out the name, this will need to be revised for deaf women. Ensure the reception team inform you of her arrival and position the women where she can see you.

When we think about the appointment itself, deaf women may require longer appointments. This is especially true for deaf women who use BSL but where you have not provided an interpreter. Concentration or listening fatigue means women who are trying to lipread English will struggle to take in and retain all the information you have provided. Remember, BSL is very different, grammatically from English, so writing things down or giving out leaflets may not be enough.

When providing antenatal classes, if a woman requires a BSL interpreter you will need 2 interpreters for any class longer than 20 minutes.

It is worth knowing that sign language is not international and you may need to provide a sign language interpreter for a foreign signed language. Sign languages can be as different from each

other as spoken languages are, for example, American Sign Language is not at all like British Sign Language.

I would like to take a moment to talk about domestic violence. If you are relying on a partner to support communication with a deaf woman, how are you ensuring that she is able to disclose safely?

According to deaf charity, Sign Health, deaf women are at twice the risk of DV but are less able to get help. Sign Health have Domestic Abuse services in BSL and also provide services that are sensitive to the needs of the deaf BSL community.

For deaf women who do not use BSL, ensure that you are also providing information that does not require them to call for help. Check whether the services you advise have a text, online chat or email provision.

This information also applies to mental health services. Deaf people are twice as likely to suffer with mental health issues and they may struggle to access mainstream help. Texting SHOUT to 85258 allows deaf people to communicate by text. Furthermore, if they text DEAF to 85258 this will alert the volunteer that they may need alternative services, like those provided by SignHealth.

If we move now to inpatient services, I would first like to talk about BSL interpreters for Labour and Birth. Most trust require a time period for booking an interpreter which ranges from 3 days to 3 weeks depending on the trust. Other trusts have moved to a purely online provision.

There are several factors to consider here. If your trust uses face to face interpreters, a plan is going to be needed for how this can be provided in labour.

I will give one example I have heard from a deaf woman. She asked a group of interpreters she knew and trusted to join a WhatsApp group. They all ensured they were registered with the hospital interpreting service. When the woman went into labour, she texts the group. When she arrived at the hospital, one of the interpreters also arrived. The triage midwife needed to put in a booking request in the normal way, which the available interpreter then picked up.

This is one way that deaf BSL using women have been overcoming the barriers created by booking services.

For trusts who use online provision, this is one way of being able to provide flexible 24 hour provisions but ensure that you know how to access it and that you are in a room with a computer that is located where the woman can see it.

This brings me onto the triage services. How do women access your maternity services for help? Is it via a triage helpline?

Deaf women may be unable to call triage for advice and help and so this is likely to increase the number of unnecessary visits to the hospital. It may also impact their labouring experience if they have to come in and go home multiple times. Some trusts do have email or text services but these are not always manned 24/7 and so deaf women are left without the same provisions as hearing women for accessing help.

It is worth bearing in mind that for deaf women who use BSL, 90% of their partners will be deaf BSL users themselves so we cannot rely on the partner being able to call.

Once a woman has been admitted in labour, how do we continue to give accessible care? Fortunately, a lot of midwifery care relies on more than just the spoken word and can continue to be provided through touch and body language.

Some key things to think about in labour are:

- Some pain relief options can make women drowsy and this will have a significant impact on ability to lip-read, sign and follow an interpreter (especially an online interpreter).
- Epidural siting will take more thought as it needs to be fully explained and communicated prior to starting. You may also need a 2nd person in the room to assist the anaesthetist while someone supports communication with the woman.
- Consider where you place an IV cannula for women who use BSL. The wrist and antecubital fossa can make signing difficult.
- Deaf women are normally more reliant on visual information and so you will need to give time for women to lip read/watch the interpreter and then look at whatever you are doing or describing.
- Pictures may be beneficial for deaf women, for example, drawing the position of the baby.

If we think about emergencies, these are overwhelming for all women, but these can be particularly distressing for deaf women who may not able to pick up what is going on from your conversations.

- Consider explaining what happens in an emergency early on, if not antenatally.
- Consider giving a woman a blank consent form to read in advance and explaining the different parts so she knows what to look for when signing. A deaf women cannot read and listen in the same way hearing women can and so they will need more time to receive the information (something we do not always have).
- A BSL interpreter should not be counted as the support person. Women should not have to chose between communicating and having their partner there. Either in the birth room or in theatre.
- Someone will need to be assigned to communicate with the woman if they rely on lip reading. This includes explaining discussions that are being had about them.

During COVID, how will you communicate with deaf women if you are wearing a mask? It is worth asking your trust to provide visors, or clear mask that have been PPE approved are available.

During labour, it is worth coming up with a communication method for the second stage. Explain to women what you are going to asks them to do and discuss a useful communication method that works for them. Examples include, squeezing their hand for push, pulsing for short breaths and letting go for stop pushing. Another example is asking their partner to blow on their cheek or neck. Touching their leg or back if all 4s for push, tapping for stop. The list is endless.

Finally, postnatal care. A lot of the deaf women I have spoken to have found care on the postnatal ward challenging. One of the reasons for this is being in situations that have made them feel like a bad mother. One woman described using the vibrating pillow – when the baby cries a special cot

mattress was provided that detects this and alerts the mother through a vibrating pillow. However, other mothers in the bay were able to respond to their babies much sooner and would keep telling the deaf mother to look after her baby.

Consider putting deaf women in a side room to support them in caring for their baby without pressure.

Another woman told me a story about her meal being provided while she was asleep and no-one woke her. The catering staff told her that they were not allowed to touch her and so could not wake her up. If this is true in your trust, ask to be informed if a meal is provided and the woman is asleep.

Finally, postnatal care at home. The same issues from antenatal care around communicating, accessing support and postnatal clinics continue through to outpatient postnatal care but some additional things to consider are:

- Resources for deaf families – how does your local area provide the equipment that deaf families need, for example, vibrating pillows, or baby monitors with flashing lights.
- Breastfeeding support - A lot of breastfeeding support services are now led by volunteer groups and therefore they do not have the funding to provide interpreters or give the 1:1 support needed for those that rely on lipreading.
- PN depression – if deaf people are twice as likely to have mental health issues then we have to consider the impact on PN depression in the deaf community.

There is a lot to think about to make maternity services truly accessible and the examples I have given here are based on my conversations with deaf women and their families. This is not an exhaustive list of what deaf families may need but a good starting point to open the conversations.

Often it is the little things that make a big difference and the simplest thing you can do is listen to deaf women and support them overcome any barriers.

Thank you for listening.