AIMS
JOURNAL

The deafness loop:
a cycle of inequality

Volume 36, Number 4 2024

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Journal Vol. 36, No. 4
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Editorial: Hello and welcome. How are you?

by Alex Smith

Sign images from british-sign.co.uk

Welcome to the December 2024 edition of the AIMS journal. The theme for this quarter considers the experience of care for deaf[1] parents and also for parents who discover that their baby is deaf. We have called this issue, '*The Deafness Loop* (with a nod to the hearing loop): *a cycle of inequality*'. This is because the inequalities that deaf babies born today will face from birth and throughout their education, are directly connected to the inequalities that Deaf parents face throughout their maternity care.

As we know, feeling traumatised after a poor experience of maternity care is a growing problem. [2, 3] Communication issues are often implicated in lasting feelings of trauma, and MNSI (the Maternity and Newborn Safety Investigations group) says that: *"Communication is a key patient safety systems issue in maternity care, as well as being a significant determinant in families' experiences."*[4]

If determined, well-prepared, hearing parents find it hard to communicate and to be heard, just imagine how much harder it is for Deaf parents - especially those with British Sign Language (BSL) as a first language.

Meghan Luton who writes in this issue, has conducted research[5] showing that compared with hearing parents, Deaf parents are less likely to have incidental knowledge about healthcare systems, about their rights, and about medical terminology. Incidental knowledge is the sort of knowledge acquired from overheard discussions, chatting with friends, or from television and radio. This means that Deaf people are more likely to be attending appointments without even knowing why. They may ‘consent’ to a procedure without knowing its purpose; for example, they may think an examination is a routine check when it is actually the first step of an induction. And Deaf women are less likely to speak up for themselves.

This shocking situation is also explained by recent research that reveals a discrepancy between midwives’ actual knowledge of legal consent (poor) and their self-perceptions of their knowledge (excellent). It concluded that midwives urgently require further training to ensure that their consent practices are compliant with the law.[6]

For anyone - parent or practitioner - this is a reminder about medical consent.[7, 8]

- Your consent is required for every test, examination, procedure or treatment.
- Consent is only validly obtained when all reasonable options are on offer, including the option to say no to any or all of them, in other words, the option to do nothing.
- Consent is only validly obtained when the medical practitioner takes reasonable care to ensure that the person understands the actual balance of risks and benefits between each option.
- Consent can be withdrawn at any time before or even during a procedure and the practitioner must stop immediately if you have asked them to. Of course, in some situations there may be a ‘no turning back’ point, for example, once a caesarean incision has been made, but even then the surgeon should pause and listen to your concerns.[9]

If this is new information, give yourself a moment to absorb it. Tea?

The following uninformed or reluctant ‘agreements’ are not consent.

- Agreeing to care without knowing its purpose - is not consent.
- Agreeing to something without feeling you have an option - is not consent.
- ‘Coaxed-compliance’ - compliance gained with smiles and gentle words - is not consent

- Compliance gained through veiled or partly veiled threats - is not consent. “Yes, you do have a choice, but we don’t want anything to happen to the baby, do we.” Is like saying, “Do as we say, and no-one gets hurt.” It is a hostage situation.
- Saying yes to something when the risks have been overinflated - is not consent.
- And ‘NO’ conveyed as facial expression or body language still means no.

This needs to be crystal clear to every health practitioner and every service user - including BSL users and BSL interpreters. If every hospital, surgery or clinic waiting room had a screen with consent being explained in BSL, *with voice and subtitles and other language options*, both Deaf and hearing service users, as well as the staff who would see this every day, would be reminded. This video from the Scottish government, but relevant throughout the UK, explains medical consent and the patient’s rights in BSL.

Meghan’s research[5] also shows that Deaf women are more likely to delay or avoid care (a fact that is also true for Deaf women in the States[10] and probably globally[11]) and that satisfaction with care decreases as the number of appointments increase. This makes good sense. If appointments feel rushed, impersonal, uncaring, confusing and insensitive, and when Deaf parents feel powerless, then lying low seems entirely rational. Deaf women are often routinely treated as ‘high risk’, denied access to physiology-informed care, and experience invasive procedures without any choice in the matter.[12] It must feel like walking into the lion’s den. While hearing women have the option of calling for a quick chat to sort out concerns, Deaf women do not. One-to-one midwifery would enable the midwife caring for a Deaf woman (and/or her Deaf partner) to understand this person’s preferred method of making contact so that communications can be straightforward and timely, but less than one quarter of women in the UK benefit from seeing the same midwife at each visit.[13]

Neither Deaf nor hearing women have any legal obligation to engage with the maternity services more than they wish to. However, the research shows that the minority of Deaf women with health conditions that would benefit from good medical care is somewhat higher than it is for hearing women. This makes it particularly important that everything should be in place to ensure that Deaf women feel welcomed, respected and able to communicate freely and without rush. To this end, a professional, specialist interpreter is essential.

Sign Language Interpreters are highly qualified. They have level 6 in BSL and Interpreter training on top of that, but as of November 2022, there were only 908 registered BSL interpreters and 234 trainees. Research shows that accessing an interpreter in a healthcare setting can be difficult.[14] Some NHS trust websites require anything from 3 days to 3 weeks notice for bookings, and when an interpreter is not available, is delayed or does not appear, family members, or staff with very basic BSL, may be used instead. This is not always sufficient or safe. Online BSL interpreting agencies like SignLive and SignVideo can be more instantly available - presumably woefully inadequate in these situations but possibly better than nothing.

A good interpreter makes all the difference, but one thing an interpreter isn't is a doula. If the doctor or midwife says, "I need to examine you now", the interpreter signs just that. In some ways the mother is being told twice. The interpreter does not add, "But you can say no." If the mother looks reluctant, but submits, the interpreter does not intervene to remind the doctor or midwife to go through the consent process properly. This would be against their professional code. The hospital is funding the interpreter and in some ways the interpreter is supporting the status quo.

The British Sign Language (BSL) Act 2022[15] means that there is now a legal duty to provide the correct communication support for Deaf British Sign Language users in the UK. But, according to Lesley Weatherson whose very interesting 2022 article is republished in this issue, the Act is either being ignored, is not understood or is not known about.[16] This disregard for the law also appears to be the case for hearing impaired people who rely on spoken English, as Helen Jones found. She writes in her account:
"It was written in my notes that I was hearing impaired but no one seemed to take any notice of this."

It might be reasonable to assume that good written information would fill the communication gap, but as I explain in another article in this issue, 'Why can't we just give deaf people a leaflet?', this isn't always the case. A further page from me covers a miscellaneous selection of 'Did you know?' information about deafness and maternity. Imagining how another person experiences the world is hard. Cake?

We continue the theme of deafness and pregnancy with three contributors writing about their experience of having a baby diagnosed with deafness. In 'A child is born into the world and their world is in silence', the mother writes about her struggle to provide language for her child, and about the educational inequalities that Deaf children endure; Karrie, whose child is still very young, talks about her initial shock, and her determination to help her son develop a positive Deaf identity; and a third mother shares her appalling experience of her early encounters with the audiology department, that seem completely devoid of empathy, compassion or useful information, but ends up feeling very positive about *the results* of the care her son received. To conclude the themed section of the journal we have a delightful bite-sized article from Salli Ward, telling us about the first baby to have their BSL sign name legally recorded on their birth certificate.

Moving on, Catharine Hart reports on the Microbirth summit, and we have our regular Birth Activist Briefing, on this occasion about the Maternal Mental Health Service Progress report. Bine Browne, retired midwife and member of the Association of Radical Midwives (ARM), introduces us to the ARM's pamphlet, 'Proposals for Change : A New Era in Maternity Care'. Jo Dagustun tells us about an interesting NHS conference she attended recently, and in a further article Jo explains why AIMS is calling for a full pathway continuity of carer model of care to be a key plank of the new Government's renewed maternity transformation policy. We also have a second piece from Catharine Hart in which she tells us about the Cochrane review that compares outcomes for women and babies who received midwife continuity of care with other models of care. Last, but never least, the AIMS Campaign's Team tells us what they have been up to since September.

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[1] Editor's note: A capital 'D' is used when indicating someone who identifies themselves as culturally Deaf and part of the Deaf community. https://hearmeoutcc.com/capital-d-small-d-deaf

[2] Parliamentary Inquiry into Birth Trauma: Call for Evidence - AIMS Submission

www.aims.org.uk/campaigning/item/parliamentary-inquiry-birth-trauma

[3] AIMS (2024) Birth Trauma Inquiry Open Letter - May 2024

www.aims.org.uk/campaigning/item/birth-trauma-inquiry-open-letter

[4] MNSI (2023) Safety factors surrounding effective communication throughout the pregnancy journey

www.mnsi.org.uk/news/safety-factors-and-effective-communications-in-pregnancy

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www.nuffieldtrust.org.uk/news-item/inequalities-in-midwifery-continuity-of-care-during-pregnancy

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15 The British Sign Language (BSL) report 2022. www.gov.uk/government/publications/the-british-sign-language-bsl-report-2022/the-british-sign-language-bsl-report-2022

16 Weatherson L. (2022) Support for Deaf and Deafblind women in the maternity setting. https://maternityandmidwifery.co.uk/support-for-Deaf-and-Deafblind-women-in-the-maternity-setting

History and politics of deafness

by Meghan Luton

Author Bio: Meghan is a senior lecturer in Midwifery and Programme Leader for the 3 year programme at Middlesex University. She is currently completing her PhD exploring the maternity and motherhood experiences of deaf BSL using women.

Introduction

Deafness, defined as a partial or total inability to perceive or understand sound, currently affects an estimated 1 in 5 people in the UK.[1] Deafness is defined within four categories, mild, moderate, severe and profound.[2] At the last census, 21,971 people aged 3 and over reported using a signed language as their first language.[3]

A study of deaf British Sign Language (BSL) users found that their general health was poorer than that of the general population, with higher rates of misdiagnosis and undertreatment of conditions.[4] Furthermore, in maternity, deaf women are more likely to have caesareans or lengthy hospital stays following birth.[5] Historical issues within the deaf community and a lack of recognition of BSL as a language create complexities in self-advocacy and access to healthcare.

This article will briefly outline deaf history. It will also discuss the competing ideas of deafness as a disability or deafness as a culture to lend context to issues faced by women accessing maternity services.

Deaf History

Sign language is a visual language and so there is limited recorded historical data about deaf people. Traditionally, deaf history and deaf stories have been passed down either by the written interpretations of hearing people observing the community or by storytelling from one deaf generation to the next until they could be recorded by photography or videography.[6] There is evidence of a deaf community using a manual alphabet in the writings of Socrates and Plato.[7]

There was a perception that deafness was a curse or a punishment from God meaning deaf people were not allowed to attend church, receive an education, make wills or inherit assets from their families.[6] Finally, in 1760, a French monk named Abbé de l'Éppé, believing that deaf children should have access to a religious education, developed a "manual method" of educating deaf children.[8] L'Éppé's methods were a success and deaf children were able to leave school and get jobs as, among other things, doctors, teachers and lawyers.[8] At the same time, in the UK, Thomas Braidwood opened a school which also employed a manual language in combination with English. Braidwood saw comparable successes, with the first Teacher of the Deaf in Britain having been educated at Braidwood's Academy.[7]

However, the 18th century also saw the beginnings of a more systematic oppression of the deaf community. Samuel Heinicke, a teacher in Germany, believed that speech formed the basis of intellectual ability and that the use of signing impaired language development.[9] He developed an oral method of education, where children were taught to speak using taste, touch and vibration. Sign language was banned in these classrooms. The debate between oral or manual methods of instruction for deaf children persisted for many years.[9]

In 1880, the International Congress on Deaf Education (ICED) held their second meeting in Milan, Italy. The conference had only one deaf person in attendance and the demonstration of the oral method used children who were deafened – meaning they could already speak before they went deaf (Leigh and Marschark, 2016).[10] The students were prepared by the teachers and the audience members were not allowed to interact with the children. No evidence of the attainment of signing children was presented. Despite these notable flaws, attendees voted in favour of oral only education for deaf children (Leigh and Marschark, 2016). This led to an immediate and widespread ban on sign language in education. It also resulted in the immediate loss of jobs for large numbers of deaf people, in particular, deaf educators.[11]

Deaf adults across the years have reported being tied down to prevent them from using their hands, and years of speech and language therapy that forced them to learn to speak.[12] This resulted in large numbers of children leaving school with little to no functional education beyond being able to make sound.[7] This left them in limbo between a hearing world they could not fully access and a deaf world that they could not fully communicate within.[13]

The ban on sign language in education continued until 1980 but it was not until 2010, that the ICED formally rejected the 1880 resolutions and acknowledged the harm that had been done to generations of the deaf community through its actions.

BSL as a recognised language

The legal recognition of sign languages has been slow to achieve.[14] In the 1960s, an American linguist proved that American Sign Language (ASL) was a fully formed and grammatically sound language, distinct from American English.[15] His work inspired similar research in the UK. However, it was not until 2003 that the UK government recognised BSL as a language. Scotland's British Sign Language Act was introduced in 2015 and, after significant campaigning, the British Sign Language Act was given royal assent in April 2022 and came into force in June 2022.[16] The Act recognises BSL as an official language of England, Wales and Scotland. Work is now ongoing to ensure that the Act gives deaf people their legal right to information in their first, and sometimes only, language.[16]

Deafness as a disability

Following the decisions of the 1880 Milan conference, deaf adults were no longer able to educate deaf children and pass on deaf history or culture.[17] Society saw deafness as a disability and something in need of a cure.[11] Rather than being educated and integrated members of society, deaf people had to conform to the hearing world by speaking and "hearing" via aids and lipreading.[11] The medical model of disability was applied to deaf people. Medicalised discourse romanticises people who are seen to overcome their disability and promotes the idea that everyone should aspire to be "normal".[17], [18] The medical model places a focus on curing or removing the impairment. In the case of deafness, by using cochlear implantation or genetic screening.[19], [20] Disability is seen as personal loss or a tragedy that has befallen the individual.[21]

Conversely, the social model asserts that people had (and have) disability imposed on them by structures that "unnecessarily isolated and excluded [them] from full participation in society".[22] These structures include societal perceptions, building designs or governmental policies.[23] For example, a deaf person missing a train due to a platform change being announced over a tannoy system rather than displayed on the platform screens. In this example, the deafness is not necessarily the issue but rather that the train station did not display the information in an accessible way.

Critics of the social model highlight that it oversimplifies the issue of disability, creates a binary model and links all disabled people together as a homogenous group.[24], 18 It cannot be assumed that people experience the same issue in the same way or that there is overall shared experience of disability.[18], [17],[25] Oliver and Barnes (2012)[21] highlight that it is unrealistic to say that all socially created barriers can be removed thereby resolving all issues for disabled people. Much disability research is now moving away from a binary approach and tries to understand disability through both the medical and social issues unique to an individual.

Deafness as a cultural identity

It is important to recognise that many deaf people do not identify as disabled at all. Many profoundly deaf people may feel part of a cultural and linguistic minority, particularly when they use BSL as their first language.[26] Previous studies have used the term Deaf, with a capital "D", a noun, used to denote a cultural identity. Deaf with a small "d" was used as a descriptor of hearing status rather than identity. This approach is well recognised in the literature. However, in line with the criticisms of disability models, it is coming under criticism for oversimplifying the complex issue of identity within the deaf community.[27],[28] For example, Davis (1995)[17] argues that someone may be deaf and primarily use BSL but not feel that they are a member of the Deaf community. Alternatively, the hearing Child of a Deaf Adult (CODA) may have been raised with BSL as their first language, be a member of the Deaf community but not have the same issues owing to being able to hear.

In the Deaf community, terms such as "hearing impaired" or "hearing loss" may be considered offensive.[29] Deaf people may argue that they are not impaired, nor did they have any hearing to lose. Despite this, medical literature and national guidelines continue to use the term. This forces deaf people to attend "hearing impaired units" at school or tick "hearing impaired" on health questionnaires.[30] In response to the term "hearing loss", the term "Deaf Gain" was coined in the 1990s. Deaf Gain argues that there are advantages to being deaf that include a shared language and identity, a global community and a different perspective of the world.[31]

More recently, the commercialisation and misrepresentation of sign language in the media and by hearing people for their own gain, has become an important topic in the deaf community. In particular, hearing people with limited signing experience (for example, having learnt level 1, a qualification predominantly focussed on vocabulary rather than grammar or culture) using BSL to promote themselves on social media (SeeHear, 2020)[32] or using "fake" sign language. Further to this, mainstream media frequently use Makaton or Sign Supported English (SSE) interchangeably with BSL (BBC Newsbeat, 2019).[33] Makaton and SSE are both invented communication tools designed to support communication in English, whereas BSL is a naturally occurring and legally recognised language.[34]

The advent of baby sign has also brokered debate in the Deaf community. Baby sign is used by hearing families to improve language acquisition in babies by signing important, key words.[35] This comes after years of the families of deaf children being told that signing will harm language acquisition.[12] This has caused frustration in the deaf community, who were denied access to their own language or have been told that their own deafness will lead to language delay in their hearing children.[12], [35] While baby sign is actively promoted and encouraged for hearing children, deaf children are still being denied access to sign language.[36] They continue to have their language development assessed in English without recognising acquisition of BSL.[37] Furthermore, the argument persists that parents must choose between oralism or sign language and that a child cannot or should not acquire both.[36]

Even within the deaf community, finding consensus is complex and there are many different and even opposing views held. While some groups are calling for bilateral cochlear implants (CIs) to be provided to adults on the NHS,[38] other groups discuss how CIs and other "cures" are a form of ethnic cleansing.[39], [40] Deaf BSL users, who identify as members of a deaf community, argue that, when integrated into the deaf community, they are not disabled, and that rather it is the hearing non-signers who are the ones who are impaired.[41] However, this idea is complicated by the way that accessibility support is provided. For example, many young deaf adults say they do not identify as disabled but to get support to attend university they must apply for Disabled Student Allowance.[42]

Developing a "deaf identity" is a complex issue. Deaf children born to deaf parents will acquire their culture naturally through a shared language and world view.[12] However, 90% of deaf children are born to hearing parents.[43] A desire to have a shared family identity combined with the increased use of CIs and other aids can lead to deaf children identifying as hearing.[44] Sometimes, when a child is not able to cope in mainstream school, the shift to a deaf unit or even a deaf school can be a shock. Children may feel a sense of grief to find out that they are “deaf” and not “hearing”.

Many deaf children do not experience deaf culture until much later in life. In a recent programme about students at Gallaudet University, a deaf university in America, it was clear that there are ongoing issues with young deaf people finding their deaf identity.[45] Students talked about not realising there was a culture that they could be part of until arriving at university. Some students then decided to dispose of their aids and fully join the deaf community. Other students reported feeling a deaf hierarchy predicated on how well you represented being “deaf”. For example, deaf signing children with deaf parents were considered “more deaf” than deaf children who used oral methods of communication. They also felt pressure to conform to a fully deaf identity when they felt that using a mixture of communication methods helped them to navigate the hearing and the deaf world.

It is important to recognise that literature by deaf academics has shown a focus on issues of audism, [46] hearing privilege and cultural appropriation since the 1980s. These conversations may put deaf issues more on par with minority culture debates.[47] This means that deaf people may be an oppressed linguistic minority rather than a disability group.[12], [11]

The health of deaf people

Deaf people are less likely to have general knowledge about good health and healthcare systems.[48], [49] This is likely due to the fact that they do not pick up incidental information such as overhearing dinner table conversations and have limited access to interpreted or subtitled media.[47], [50], [51] The research that informed the 2014 Sign Health “Sick Of It” report[52] found that the health of the deaf signing population in the UK is poorer compared to the general population despite lower rates of smoking or alcohol consumption.[4] This study found higher rates of misdiagnosis and that deaf people were unwilling or unable to attend their GP as often as they wished due to not having access to adequate communication.[4]

When looking at maternity care, there is limited data about pregnancy outcomes for deaf women. Two American studies looking at the outcomes for deaf signing women found they were more likely to have a caesarean section, or an increased length of hospital stay following vaginal birth.[5], [53] One of the studies further found that deaf mothers were more likely to have pregnancy complications such as placental abruption or pre-eclampsia.[5] They were also more likely to have pre-existing hypertension or diabetes.[5]

It appears from these studies that deaf women are more at risk of complex, and potentially traumatic, births that result in longer hospital stays. While it is difficult to apply these finding to the UK population, the Sick Of It report found deaf BSL users, a sample which included women of childbearing age, were more likely to have hypertension or diabetes (Emond et al, 2015), a factor which could be contributing to the poorer outcomes noted.

Deaf women report similar rates of mild to moderate postnatal depression (PND) but are less likely to report severe PND.[54] The researchers suggest that this may be due to not wishing to report PND for fear of being seen as a bad mother or not having access to the resources to report. It may also be because deaf mothers are often part of a community and so have access to culturally sensitive peer support from other women.[55] Research and statistics exploring PND specifically in the deaf community is lacking, but it is notable that rates of mental health issues are reported to be two or three times higher in the deaf community than in the general population.[56] There is little current, up-to-date UK based research exploring the experience of deaf BSL using women accessing maternity services specifically. The challenges faced by both deaf women and the midwives who care for them are unique to the circumstances they face and so other healthcare guidance, while applicable in many scenarios, cannot address all the concerns that deaf women have when pregnant, giving birth or being a mother.

Conclusion

This article has offered a summary of research into deaf history and culture in order to highlight that the deaf community is not a homogenous group for whom a single policy approach will work. Midwives and other maternity care providers should have an understanding of the multifaceted complexities arising from the family a deaf woman is born into, their access to language and education and their healthcare literacy. By doing so, they are better able to work with women and their families to produce individualised care plans, including communication and education needs.

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Support for deaf and deafblind women in the maternity setting

by Lesley Weatherson

Author Bio: Lesley Weatherson is a specialist BSL interpreter; lipspeaker; Deafblind communicator/guide; qualified midwife and nurse.

The current provision for women and birthing people who are deaf within the maternity setting is far from acceptable. There seems very little passion for change despite the efforts of many. Midwives want high quality care for all those in their care and communication is at the heart of this. Deaf women and birthing people want to establish a rapport with their midwives, make informed decisions about their pregnancy and delivery. Communication breakdown often prevents a truly holistic birthing experience.

The British Sign Language (BSL) Act 2022[1] means that there is now a legal duty to provide the correct communication support for deaf British Sign Language users in the UK but the Act is either being ignored, is not understood or is unknown. This affects deaf and deafblind people. Deaf women avoid seeking care, have a lack of access to health information and indeed, healthcare providers, including midwives, have a lack of deaf awareness. For deaf women, during pregnancy, birth and postnatal, this can mean having longer hospital stays and more complex needs in both the hospital and community setting.[2]

The introduction of the Accessible Information Standard[3] advised health professionals to ask about and document each patient's preferred communication needs.
From 1 August 2016 onwards, all organisations that provide NHS care and/or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying,

recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

One hoped this would see a real shift in the provision of the correct communication support within medical services. I wrote an article for The Limping Chicken back in March, 2019 hoping provision of communication for deaf and deafblind parents would have changed; sadly, not enough has improved.

The Sick of It report, published by Sign Health in 2014, shows that:
Deaf people are suffering from preventable and potentially life-threatening illnesses due to access limitations, misdiagnosis, and poor treatment.
Misdiagnosis and poor treatments are costing the NHS millions each year. According to the 2007 Saving Lives report, twenty percent of maternal deaths between 2003–2005 were of women who had late or infrequent antenatal care.[4]
The NICE Antenatal guidelines fail to mention recommendations for the care of deaf women only referencing how information should be imparted.
1.1.2 “Ensure that the materials are available in different languages or formats such as digital, printed, braille or Easy Read”
It doesn’t mention BSL.

I have undertaken numerous training activities for both British Sign Language (BSL) interpreters and directly with colleagues and midwives, and lectured to many senior midwives regarding the importance for everyone of understanding their own health. However, effective communication and the rights of access to health information for deaf people is still below an acceptable standard.

Language agencies who are responsible for filling interpreting requests don’t always understand the differing needs of deaf and deafblind people so often that the wrong communication professional attends, or none at all. The large spoken language agencies on the national framework do not always understand the various cultural and communication needs of deaf and deafblind people. I know this from personal experience as I am a qualified BSL interpreter, lipspeaker and deaf blind communicator and often turn up for a booking requiring one skill after being booked professionally, for another.

Language agencies making requests do not always give out the name of the deaf person (correctly so), or the ward/department for the booking, stating that GDPR prevents this being allowed. This causes problems as interpreters may simply delete the request citing lack of information, contact the agency only to be told there isn’t any more information that can be shared, or accept the booking not knowing if they are the best person for it. Female interpreters can end up on male urology wards and male interpreters on gynae wards; all equally qualified to do the job but not necessarily acceptable for the deaf person. If the woman refuses to use the attending professional, she may be considered awkward or problematic and this may affect further support and the midwife/patient relationship. If she continues with the appointment she may not engage, may miss important information or both. This has to change.

Frameworks don't work in my opinion, and in 2015 I signed the open letter to Francis Maude MP (2015) as part of the campaign to Scrap The Framework. However, little has changed and it remains that deaf people are not always getting the support they need and interpreters are still experiencing poor terms and refusing to work for some agencies, thus reducing the availability of qualified and adequately trained professionals.

Practical changes must be made. Policies must include a mandate for the correct communication support professionals to be booked for all appointments with the responsibility lying with the health care professionals. Deaf parents must have alternative ways to contact health care services. This is necessary and must include access to other support services such as those for people requiring breastfeeding support, or for people with unplanned pregnancies, and also to support services for victims of rape, domestic violence and so forth.

Once seated inside the hospital, deaf women or birthing people can wait, unseen, for extended periods of time as they are unable to hear their name or number being called. This leads to frustration and unnecessary delays in being assessed, and this is particularly serious when there is a medical emergency such as lack of fetal movements or vaginal bleeding. Even when they are seen on time, if there isn't an interpreter present the appointment may be abandoned. This is particularly so if BSL is the first language of the parents as the midwife or doctor will not be able to ask questions of the deaf parents, nor understand anything signed to them by the deaf parents.

Ultrasound scans are held in dimly lit rooms. Lipreading is very difficult and tiring especially in poor light. I take a doll with me when supporting deaf/deafblind parents so they can feel the part of the body that the radiographer is seeing on the screen and giving information about, such as the heart chambers or the kidneys and whether it's a girl or a boy, for example. This is a particularly anxious time for the parents as the news isn't always positive or welcomed.

Well-meaning hospital staff who know some basic sign language try to make do. This often results in miscommunication and misinformation. Errors in previous medical histories may be recorded as fact and important information is never truly conveyed. This can lead to poor outcomes for mother and baby. The correct communication professional must be used.

Deaf awareness is clearly lacking in many obstetric units across the UK and deaf parents are not receiving the same care as hearing parents.

For example, here is a deaf woman's experience during the pandemic (expecting her 5th baby):

- Couldn't call to register her pregnancy and to meet the midwife responsible for her care
- Couldn't book an antenatal class
- Couldn't go in person to the GP surgery to book an appointment as it was closed
- Couldn't attend the hospital as only those with appointments could attend and, in any event, masks were being worn so communication would be impossible- she had to ask a friend to call to contact the midwife
- Was sent a male sign language interpreter despite asking for females
- Was asked to use an app to communicate with health professionals, when the app relied upon a good understanding of English language
- Was told her hearing partner should be 'ok' to act as the interpreter when she presented with vaginal bleeding
- The father was present at each and every appointment as he told the woman it was his right to be there, and she had no reason to doubt what he said was factual
- The woman lost the baby at 19 weeks
- It turned out the woman was a victim of domestic violence- the partner had caused the mother to have a miscarriage

Many parts of this avoidable scenario were preventable. Would a hearing woman have faced the same barriers?

Despite the BSL Act 2022, information available online, in written formats, and verbal instructions or advice, is often not understood by deaf parents as English isn't their first language. For deaf parents from a non-English speaking family or country, a foreign language sign language interpreter may be needed,[5] but where does one find such support? This often means that families are relied upon to interpret throughout the maternity term leaving no autonomy for the deaf parents; they will only receive the information given by the translator and this may not be accurate; intentionally so or otherwise.

An article from the British Medical Journal in 2020[6] explains:
A family member may also give you their own version of events, and their emphasis may skew the whole consultation. It can also be difficult to check the veracity of the interpretation. This could lead to a misdiagnosis.

Family members should not be used as non-professional interpreters in consultations. NHS England, in reference to primary care, states that, ‘The use of an inappropriately trained (or no) interpreter poses risks for both the patient and healthcare provider.’ And further, ‘The error rate of untrained interpreters (including family and friends) may make their use higher risk than not having an interpreter at all.

Those women who are abused or victims of domestic violence would be traumatised further by having the perpetrator inside the hospital room. Deaf women are at twice the risk of being victims of abuse and domestic violence.[7] and need accessible and appropriate support services such as Deaf Hope.[8], [9]

Of course, not all pregnancies go to term. Spontaneous and planned abortion, ectopic pregnancies an so on, mean that support and counselling may be required from very early in the pregnancy. If the medical professionals don’t know how to access support, don’t know how to ask for gender specific interpreters, or believe they can make do with pen and paper, then communication will never be effective and deaf parents will almost certainly not receive parity.

We need to see structural changes in the way we teach midwives and doctors so that the considerations regarding communication are encompassed in learning from day one. Hospital staff need deaf awareness training on a regular basis and not a token one-off teaching day that is easily forgotten. Deaf people must be involved in this cultural change when midwives and doctors are students. We must strive to make deaf awareness training mandatory, guiding lessons learned into practice so parity with hearing patients becomes the norm. Let’s have patient-centred care, make time to get things right and truly make each and every woman’s experience the best it can be.
To achieve this, I would like to see engagement from the Nursing and Midwifery Council (NMC) and the General Medical Council (GMC), with trusted deaf charities such as the Royal National Institute for Deaf People (RNID) and the British Deaf Association (BDA), communication with professional associations such as the Association of Sign Language Interpreters (ASLI) and the Association of Lipspeakers

with Additional Signs (ALAS). Let's start having those important conversations to really make a difference to deaf women in the maternity setting.

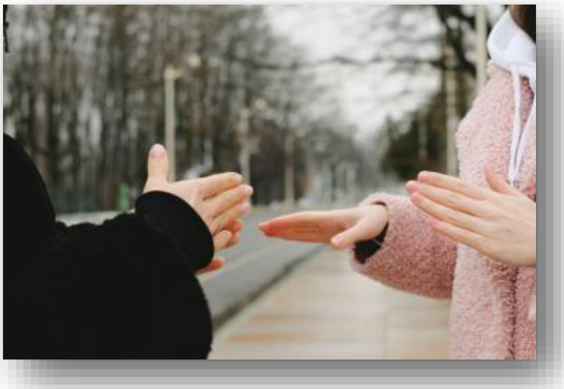
Tips for all health practitioners:

- Asking deaf parents to call if they need help or advice is not OK. Provide an accessible contact method.
- Assuming the leaflets are understood by all is not OK. Provide an accessible alternative.
- Asking if the parents want to hear the baby's heartbeat is not OK. Consider asking if they would like to feel the vibrations through the machine being used.
- Leaving food in front of deafblind mums on the ward is not OK. Ensure they know it is in front of them.
- Practising your signs is not OK. Don't assume your knowledge of BSL is sufficient to communicate with deaf parents.
- Don't say sorry if the baby is born deaf; this may be the greatest joy for the parents.

DO:

- Ask if communication support is needed, and if it is, ask about their preferred method of support such as BSL interpreters/lipspeakers/interpreters for deafblind people/notetakers.
- Ensure you book support with plenty of notice as there are so few language professionals in the UK (you may be interested to know that there are only 8 qualified interpreters for deafblind people, 55 lipspeakers and 1200 BSL interpreters in the UK).
- Ensure you can be contacted using alternative methods - not only by phone.
- Ensure each and every department has regular deaf awareness training.
- Ensure the methods you use to inform, advertise and share information is accessible to all.
- Offer the Sonicaid/CTG machine to the parents to touch when checking the fetal heart.
- Ensure your hospital has vibrating baby alarms to alert the deaf mother that her baby is crying.
- Be aware of your body language; it will be 'speaking' well before any words are spoken.
- As a matter of course, discuss the emergency situations that most commonly occur in pregnancy and birth throughout the last trimester and not as an emergency is unfolding. If, in labour, it becomes apparent that extra medical support may be required, discuss treatment options while the mother is awake and alert and able to agree and consent to a truly consensual pathway of care.[10]

- Ensure a team of interpreters is introduced throughout the pregnancy so that a familiar face is present for the birth. The same team should be used postpartum for any visits and checks on the mother or the baby.
- Make sure the interpreter is permitted into the theatre for any interventions during labour.
- Consider the use of Haptics as appropriate.
- Remember the interpreter is there because you can't sign!



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[10] Editor's note: All pregnant women, whether hearing or deaf, should understand their different care and treatment options, and that when variations of normal (or actual complications) arise, their decisions to accept or decline treatment will be respected. Consent is only valid in this way. Consent forms must reflect this and must be accessible and understandable to the person consenting.

Hearing impaired and giving birth during the pandemic

by Helen Jones-Grace

Author Bio: Helen, and her beautiful daughter Isobel, live in Wales

I was pregnant during the first lockdown and gave birth during the second lockdown in February 2021.

I am hearing impaired in one ear and wear a hearing aid. Appointments with the midwife on the telephone were not too bad as my phone is linked to my hearing aid. Face to face appointments were very difficult as masks were worn, so at times I could not hear what was being said. I did not realise how much I relied on lip reading. All appointments I had to attend on my own, so had no one to relay the information to me if I missed anything.

When I went into labour, I had to go into hospital on my own, and again, masks were worn so I was unable to understand some things that were said. It was written in my notes that I was hearing impaired but no one seemed to take any notice of this. After a couple of hours of being left in an assessment ward they realised that I needed to be moved to the labour ward. At this point my husband was able to come into the hospital. This made a big difference as I now had someone who could hear what was being said If I missed it and could take his mask off to tell me.

As a result of being left on the assessment ward and being in labour for so long my baby was in distress so it was decided that I needed to have an emergency c-section. I was told that I needed to take my hearing aid out and my glasses off. I got overwhelmed by the whole process and couldn't cope with not being able to hear or see so it was agreed that I could keep my glasses on.

After the c-section my husband had to leave straight away so again I was left on my own. Due to being in hospital for so long my hearing aid now needed to be charged. Without anyone with me I had to rely on the midwives' help. I asked on a few occasions for them to get my hearing aid charger from my bag and to plug it in for me but was told they were busy and would return soon to get it. This never happened. (Due to the surgery I was unable to get it myself)

I was then moved to a separate 6-bed room after recovery and I was the only patient in that particular room. I again asked for my hearing aid charger which they said they would return to do that, but again nobody returned. I was also not given any food or helped into bed and spent the night sitting on a chair! (This was brought up with the health board and the excuse was that due to the pandemic and staff shortages they were very busy!)

Once the change of shift in the morning had happened, everything changed and the lovely staff got my hearing aid charger from my bag and charged my hearing aid, got me food and helped me into bed!

Why can’t we just give deaf people a leaflet?

Alex Smith

Author Bio: Alex Smith is a long-time childbirth educator, the editor of the AIMS journal and a proud grandmother of a profoundly deaf grandson.

For both hearing and deaf people alike, written information (about maternity care, for example) is a one-way exchange. It does nothing to elicit the hopes, fears and aspirations of the individual, and it does not usually remind the person of their right to accept or decline some or all elements of the care described. This is where hearing/deaf equality stops.

People often assume that giving written information to someone who is deaf will help them to be fully informed, and will constitute an access to knowledge that is equal to that enjoyed by hearing people. This is not always the case. Many deaf people, especially those with BSL as a first language, find written information challenging and unhelpful.[1]

So, why would this be?

British Sign Language (BSL) is not English. It is a language in its own right. It is used by about 151,000 people in the UK, 87,000 of whom are deaf.[2]
Sign-supported English (SSE) and Makaton are different. They use some BSL signs but they are not BSL. SSE is helpful for English-speaking people who have become deaf later on.

BSL was recognised as a language by the UK government on 18 March 2003, but it took almost 20 years before the BSL Act 2022 became law.[3]

BSL is a visual language with its own grammar. It uses hand shapes (signs), body language, facial expressions and lip patterns to communicate information, tone, emphasis and meaning.[4]

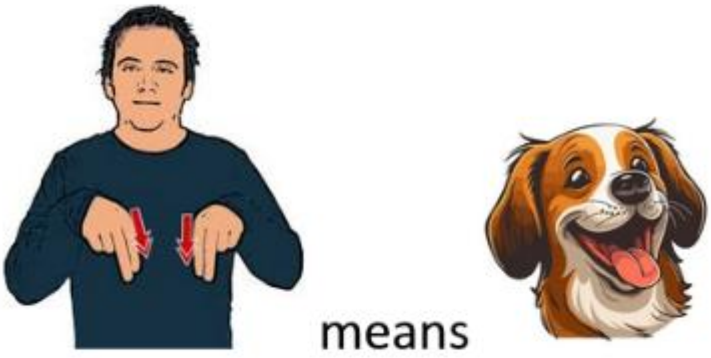
SIgn language is different in every country. For example, American and Irish sign language (ASL and ISL) are very different from BSL. A Deaf woman from Ireland visiting the UK may need an ISL sign language interpreter.
BSL has regional variations like regional dialects. Numbers, for example, can be very different around the country. As with spoken languages, BSL is evolving with each generation.[5]

The history of BSL is marked by oppression from hearing people.[6] Oppression and marginalisation is ongoing. For example, almost all teachers of the deaf, and most BSL teachers, are hearing. This is because deaf children have not been given full access to education and consequently have not been supported to gain teaching qualifications. This has far reaching implications for deaf people and for the future of BSL.[7]
In addition, the number of teachers of the deaf is steadily declining with the result that deaf children are being failed.[8] The National Deaf Children's Society (NDCS) has put out this video asking people to contact their MPs to ask for more specialist support for deaf children.

Hearing children grow up hearing spoken language around them all the time. They naturally absorb words, idioms and even abstract concepts without any effort. What about deaf children?

If a person who has been deaf since infancy was exposed to fluent sign language from birth (usually by being born into a deaf family), they will have acquired a full and rich language.

But they will not have absorbed spoken language as hearing children do. For example, the spoken word DOG has no meaning. Communication for the deaf child is visual and:



A fluent signer can almost instantly convey the size, appearance, nature and activity of the dog, with a mixture of signs, facial expression and body language.

We can begin to understand visual language if we think about someone waving from across the street. Whether hearing or deaf, we do not need to have a word for ‘wave’ to understand what is being signified by the wave. Depending on the facial expression and body language of the waver, what we see might mean: ‘Goodbye’; or ‘Hi there, I’m excited to see you’; or ‘I know you have seen me but I don’t want to stop’; or ‘Help!’; or ‘Watch out!; or ‘No thank you’; or it could even be a secret pre-arranged sign (a signal) given with a furtive look. The word ‘wave’ is not essential to the meaning of the communication. In fact, we do not need any words to understand.

BSL, however, is not the same as mime. While they share some common traits, BSL is a full language with its own grammatical structure and syntax.

When a hearing child starts to learn to read at school, the blended sounds of the letters D, O and G instantly summon the image of a dog, but also the sound memory of the spoken word ‘dog’. They have probably heard that word, linked to the presence or image of a dog, almost every day of their lives, whereas the profoundly deaf child has no sound reference for those three letter shapes. Every word may need to be learned from scratch, and learning by phonics is impossible.

This makes learning to read and write much harder and, for many profoundly Deaf adults, it remains hard - perhaps even harder than you or I would find it to read and write about important matters in a second language we learned at school.

Deaf children from hearing families may have learned to lip read, but it is estimated that only 30% to 40% of speech sounds can be lip-read even under the best conditions, and the concentration required is exhausting. Lip reading is also impossible when the speaker is wearing a face mask, or simply if they turn their head away as they speak. For deaf children with hearing parents who want to assist their child in learning English from the earliest age, a system called cued speech helps the child to lip read. Some speech sounds, like P, B and M, share the same lip pattern. Cued speech uses eight different hand shapes placed in four positions near the face to distinguish every sound visually. The advantage of providing BSL as well (but not intermixed), is that the child will be able to communicate and express their feelings much sooner with BSL and this helps their development in every way.

90% of deaf children are born to hearing parents and many hearing parents are not supported to learn sign language. For those who do manage to get to classes (and this

can be a huge struggle and expense), BSL will still always be a second language, and the child will not see other family members signing fluently with each other. This hugely limits their incidental learning, and they can all too easily feel left out of all of the important family conversation and laughter that is happening around them.
Many teachers of the deaf are not fluent in BSL and may resort to SSE (signing key words in English order). Speech and language therapists are focused on English and may not understand or value the child's ability to communicate in BSL.[9] Communication support workers assigned to help a deaf child in school generally have Level 1 or Level 2 BSL, which, in communication terms, is barely literate.[10] Deaf children of hearing parents are not exposed to fluent BSL at home *or* at school, so many are likely to grow up without a strong grasp of English or of Sign language. Deaf children desperately need strong deaf role models in order to achieve their full potential.[11]

Not having a good grasp of English does not mean the deaf child or adult is any less bright. It must be soul destroying (and life impacting) to have one's passion, interest and knowledge of the world assessed by hearing people and on hearing terms, in ways that severely limit the expression of what the deaf person truly knows and feels. It must also be heartbreaking for parents of deaf children to see them do less well than their hearing peers simply because they have not been provided with equal access to learning. It is the system's failure, not the child's, but it is the child who pays the price.

Just as a Deaf child has not been able to absorb English organically and effortlessly as they grew up, Deaf adults have not absorbed the same range of incidental knowledge about healthcare systems, about their rights, and about medical terminology as hearing people - and an information page or leaflet, rather than addressing inequality, may actually compound it. For an incredibly poignant example of this, watch Sandra's story of postnatal depression. Her video account is included in the Sign Health 'Sick of it' report.

What I would like to see:

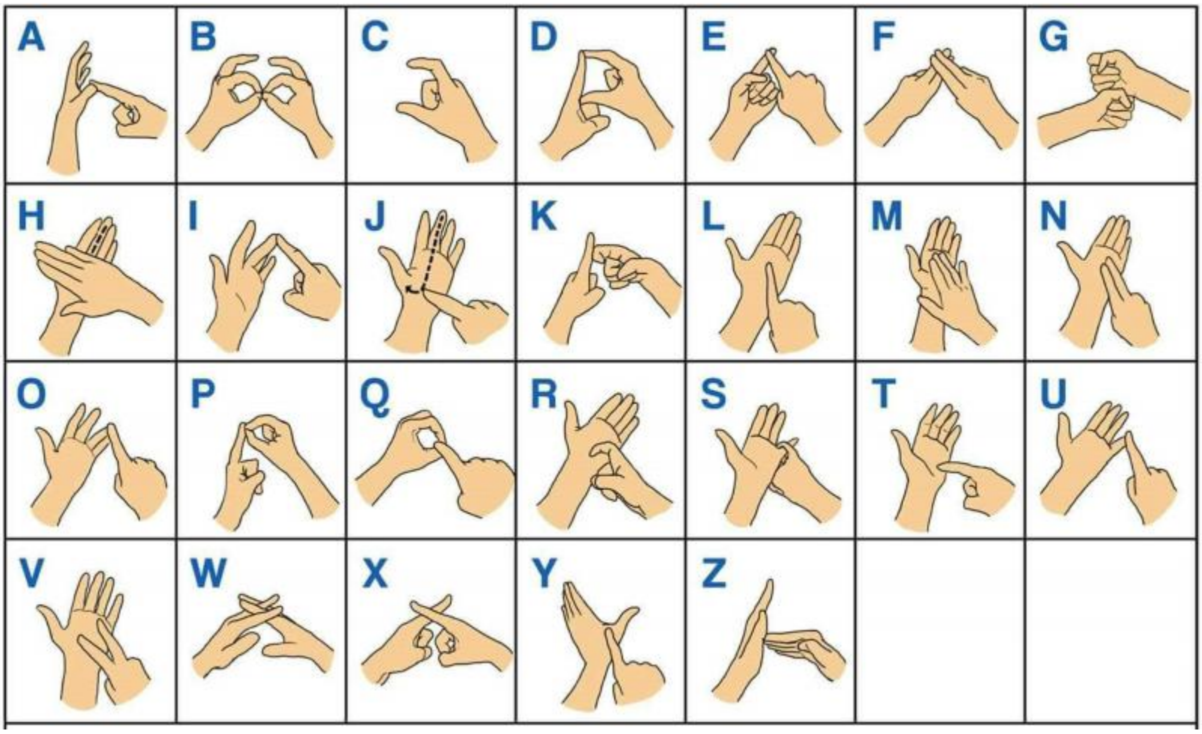
- All health information (NHS and charities) provided in BSL too - funded by the government.
- All health information presented as options and offers, with the person's right to choose or decline made very clear.
- A network of doulas emerging from within the deaf community supported by specialist interpreters.

In the meantime, what can you do as a maternity services improvement campaigner and/or health practitioner?

- Whenever the term '*equity/equality, diversity and inclusion*' is used, ask whether *all* information is also in sign language, visual images and simplified written language. Keep campaigning until this happens.
- Remind yourself and colleagues that any care given, however routine, must be *truly* consensual. Make sure that you and your colleagues routinely offer all the options and always reassure the person that their decision will be respected.
- Try to provide 'continuity of carer' and to allow more time at appointments.
- Ask the mother what she expects and needs from an appointment. Really listen to her, believe her and support her.
- If you need to wear a mask when you are caring for someone who is deaf or even slightly hard of hearing, use one that has a clear window. Make sure your unit stocks these.

- Take a Deaf-awareness course. Tell your colleagues all about it. Invite them to read this article.
- Take some sign language classes. It will help you appreciate how a basic knowledge is not enough to replace a skilled interpreter - and this will put you into campaign mode!
-

While the need for a skilled interpreter cannot be too highly stressed, learning a few basic BSL greetings shows that you care. If you have 10 minutes, why not make a start now with this
" target="_blank">video. It is very clear and introduces a useful range of basic greetings, manners and phrases, including how to introduce yourself by name and how to ask the other person's name. Names in BSL are signed using fingerspelling - see the illustration below:



This image is from Deaf Action, an organisation that offers a range of useful courses. British-Sign.co.uk also offers basic online BSL courses and useful resources for the beginner. Nothing, however, beats a face-to-face course with a deaf teacher who will also be teaching you about deaf history and politics!

This link takes you to a " target="_blank">video that teaches the BSL alphabet and shares a few tips about fingerspelling.

This page, from the Bright BSL website, has a few useful signs including: pregnant, baby, newborn, breastfeeding and so on. You will notice though that the signs for birth, contractions, labour, pain or midwife are not in their lexicon. I have found it really hard to find birth-related signs in any of the usual BSL dictionaries.

Useful organisations and websites:

- The British Deaf Association (BDA)
  Founded in 1890, the British Deaf Association (BDA) is a national Deaf-led organisation that works directly with Deaf people that use British Sign Language (BSL). Their work concentrates on campaigning for equal rights on a national level and working at a local level empowering Deaf people to achieve access to their local public services.
- British-sign.co.uk
  British-sign.co.uk offers lots of resources for people wanting to learn BSL

- BSL Zone
  The British Sign Language Broadcasting Trust (BSLBT) commissions television programmes made in British Sign Language by Deaf people for Deaf people.
- CODA UK & Ireland: Heritage, Community, Diversity
  CODA stands for Children of Deaf Adults. CODA works to bring CODAs together for social interaction and peer support and to celebrate their deaf heritage.
- Deaf Action
  Deaf Action exists to support the diversity of deaf people, including deaf users of British Sign Language (BSL), and those who are deafened, deafblind or hard of hearing. Their work is geared towards empowering all deaf people to achieve their potential and fully participate in society, with equality of rights, access and opportunity.
- Defax - Since 1985 Defax has been working to empower and enhance the lives of deaf people. They specialise in visual and interactive deaf-friendly training and resources. They have a useful deafness and pregnancy guide for health professionals.
- Deaf Choices UK
- Deaf Choices UK supports parents of deaf children and professionals to make the best CHOICE(S) for Communication, Language and Literacy.
- Deaf Ethnic Women's Association
  Deaf Ethnic Women's Association is a national organisation run and controlled by Deaf women from Minority Ethnic groups. DEWA provides a range of support and empowers Minority Ethnic Deaf women to have choice and control, be active and be successful in all aspects of their lives without compromising their identity.
- Deaf Parents Deaf Children
  Deaf Parents Deaf Children (DPDC) is a group for deaf parents with deaf children from all over the UK. The aim of DPDC is to show a positive view of deafness, to show what deaf people can achieve and to give deaf parents an equal voice in the decision making process. They want to make sure that the system currently in place is improved to ensure it is in the best interests of all deaf children.
- Disability Plus: Deaf Counselling
  Disability Plus provides support to individuals with disabilities and their carers, including BSL counselling for adults and teenagers with counsellors and psychotherapists who are either deaf themselves or who come from a deaf background and can sign fluently.
- JDA
  The JDA is an independent, national charity offering professional support services, information and a range of social, cultural and educational

programmes to the Deaf community, people with all levels of hearing loss, people experiencing tinnitus, their friends, families and those caring for them.

- National Deaf Children's Association (NDCA)
  The NDCA gives expert support on childhood deafness, raises awareness and campaigns for deaf children's rights, so they have the same opportunities as everyone else.
- Royal National Institute of the Deaf (RNID)
  The RNID is a national charity supporting the 18 million people in the UK who are deaf, have hearing loss or tinnitus. They are the only charity in the UK dedicated to funding hearing research. The RNID can be contacted for support between 8-30 and 5.00 Monday to Friday.
- Sense
  Sense provides support for anyone who is deafblind or living with complex disabilities. They have services for disabled adults and children all over the UK.
- Sign health
  Sign Health aims to promote easier access to healthcare and information. They partner with the NHS and other services and take on projects, carry out research, and raise awareness. They have useful health information videos in BSL. They also deliver their own services to reach deaf people in their moment of need, through domestic abuse support, therapy, advocacy and residential services.
- Terptree: changing the world for deaf people
  Terptree provides Communication and BSL Interpreting Services across the UK. They also provide training and have a focus on improving deaf people's lives in the workplace and in education. Their page on how to work with a BSL interpreter may be useful.

[1] Vale C. (2021) Making written communication accessible for Deaf customers and clients (with BSL) https://limpingchicken.com/2021/03/19/clare-vale-making-written-communication-accessible-for-deaf-customers-and-clients
[2] Gov.UK (2023) The British Sign Language (BSL) report 2022 www.gov.uk/government/publications/the-british-sign-language-bsl-report-2022/the-british-sign-language-bsl-report-2022
[3] British Deaf Association (2022) BSL Act 2022 update. https://bda.org.uk/bsl-act-2022-update
[4] Access BSL (2024) How Do You Sign Sentences in BSL? https://accessbsl.com/how-do-you-sign-sentences-in-bsl
[5] BSL Zone (2024) Evolution of BSL https://www.bslzone.co.uk/watch/evolution-bsl
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[8] National Deaf Children's Association (2024) Consortium for Research in Deaf Education (CRIDE) reports www.ndcs.org.uk/information-and-support/professionals/research-and-data/cride-reports
[9] Withey R. (2024) Insight: I pulled my deaf child out of speech therapy https://limpingchicken.com/2024/02/21/insight-i-pulled-my-deaf-child-out-of-speech-therapy-bsl
[10] DPDC (2012) Level of Communication Support Workers/interpreters in schools. https://deafparentsdeafchildren.co.uk/dpdc-tips
[11] Gibbs A. (2019) We need more visible Deaf role models. Limping Chicken https://limpingchicken.com/2019/02/25/amy-gibbs-we-need-more-visible-deaf-role-models

A conversation with Karrie whose little boy is deaf

Interview by Alex Smith

Author Bio: Karrie lives in Scotland with her husband and two sons. The whole family loves good food and quality time with other people, and are all on a journey of learning about deafness.

Hello Karrie, thank you for agreeing to share your experience with us. Many congratulations on the birth of your second baby. He is fifteen months old now I believe. How did you first find out he was deaf?

We found out our child was deaf through the newborn hearing screening programme. Every child in the UK is tested at birth for deafness and this programme is a game changer for those with hearing loss as it gives early access to technology and support. They came around the ward and explained that this was a quick 30-second test to check for hearing problems, but, like many babies, he failed the first time round. They repeated the test and he failed again, but we were really reassured because a member of staff said that many newborn babies were still full of snot and that this would clear. I felt okay, but what's funny was that the week before he was diagnosed I'd watched a BBC documentary about the profoundly deaf actress Rose Ayling-Ellis. I asked my husband if he thought our child was deaf, but at that point we both felt he was probably fine.

It was after this that I attended an appointment with a person in a suit. You know in the NHS that you don't get given a person in a suit for nothing. So we got given a man with a suit who was actually really lovely and kind and he said this is a sixty-minute appointment, not the twenty minutes I was expecting. The ABR hearing test[1] process was simple. I breastfed my baby to sleep and the audiologists were really patient. They wait until the baby is asleep and then they attach electrodes and triple check everything. They are looking for brain activity in response to sound. I watched it happen. They put a tiny little video on the screen showing the read-out of the test. Whilst asleep, babies should have very calm brain activity, and when they hear sound, the lines on the read out should start dancing up and down. I could clearly see that there was nothing. Even when the volume was as loud as a jackhammer he was still sleeping and the lines were not moving. Sixty minutes came and went. The audiologist said we could keep going as the next patient hadn't turned up, and after another 45 minutes the tests were completed and the audiologist confirmed that our child had bilateral severe to profound hearing loss. (His classification has since changed to moderate to severe).

Actually he didn't use the word deaf, which was really interesting. I just sat there a bit shell-shocked and went home. It was probably a couple weeks before I figured out that I was allowed to use deaf in relation to that degree of hearing loss. A friend congratulated me for switching to the term deaf that day.

A few hours later my husband came home from work and we sat down at the kitchen table and I said, “Right then, what do you think, deaf or not deaf?” and he said, “Oh is this a kind of bad joke?”. It took us a while to take on board that this was for real. So that was our experience of diagnosis.

How supported did you feel by the health professionals involved at that point?

I have to say the audiologist was really good. He started explaining about the anatomy of the ear but I was asking the same questions over and over again. I desperately needed to understand everything in order to be able to share all this information with my husband and our wider family. He was really helpful and, at my request, fetched pictures and an audiogram[2] to show me. He went through ear anatomy about three or four times. I learned that it was a sensorineural hearing loss and I now understand what that means.[3] My experience of diagnosis was really helped because our appointment was extended, the audiologist took the time to go over everything repeatedly, and because, in that moment, I had the forethought to ask for some pictures.

I can only imagine how different your experience would have been if you had felt rushed. What sort of emotional impact has your child’s diagnosis had on you and your family?

I think it's a slow burn, understanding disability. To start with I was shocked and a bit sad to think that there's all this sound around us that my child can't hear, but I quickly made a conscious choice about how I was going to process it all. One decision I made very early on was to acknowledge that many disabled people in our world have great lives. I'm not saying that deafness is not hard, it can lead to exclusion and isolation and all sorts of problems, but I realised that I wanted to raise my child to own his disability and not be ashamed of it.[4] After all, putting on a pair of hearing aids is no different to wearing a pair of glasses. One of the things that helped shift our perspective was listening to a podcast with someone sharing their personal experience of having a visual impairment.

The person was so empowered and I thought, “Do you know what? We need to change our view on these things, it's not all bad.” It is still sad to think our child can't hear, but learning about someone else's amazing story of sensory loss was incredibly helpful.

Thinking in that positive way helped me as I was actually super-shocked at first and got tired very quickly, especially as I was having to explain everything to my family. I even made some videos - “Here's a top fact about our life”, and I joked when I went into a new social setting, or with people I hadn’t seen for a while, that I should just wear a banner saying, “Yes, he's deaf - Yes he wears hearing aids - No, he's not suitable for a cochlear implant - Yes, the hearing aids work”, you know, the top ten questions, because I knew I was going to be answering those again and again and again. That’s not a bad thing and I'm really ‘pro’ explaining our story to people, but it is very tiring.

There is quite a political stance in the deaf community about whether deafness should be considered as a disability or not. Deaf parents are often very pleased to discover their baby is also deaf because then they're normal - like them. Perhaps deafness is only a disability when considered within the context of a hearing world. What are your thoughts?

I agree. Deafness is something we live with and yes, disability is shaped by the environment around us, isn't it. I think the best thing that we can do as parents is to teach our child to own it. How many times in the day would you love to turn off the sound around you? I was in a really busy place this morning that was so loud and overstimulating that it felt like it would be good to be able to turn off the sound. I actually sometimes think of deafness as a bit of superpower. It's like a better way of viewing the world isn't?

How supported have you felt by the health professionals since the original diagnosis?

My local health board is doing pretty well to be fair, though I completely acknowledge that this is not everybody's experience. Health boards across the UK are all delivering very different services to their deaf children. I have heard stories of other people who have not had the same experience as us. Every health board should examine the quality of service they're delivering. We have also been really lucky with our health professionals. We first saw the audiologist when my son was six weeks old and he was retested at ten weeks. We changed to a different member of staff at that time and she has remained with us ever since and has been excellent. Our audiology service assesses hearing, which is an ongoing process, as well as providing our hearing aids and giving us advice on living with hearing technology. It has been really good. At times we've had to wait for appointments because they have been very busy, but I know they're always at the end of a phone. Our audiologist has spent time getting to know us as people and has given us good quality care. She has made sure that we've had an understanding of hearing aid technology and of the impact this would have on our lives. So yes, I can't fault our audiology department.

Every child who gets a diagnosis of deafness is allocated a teacher of the deaf. Ours is really sweet; my son likes her and she likes him. She gives us useful tips. One of the things I really love about her is that she's deaf herself. What better person to teach you about deaf life than a deaf person? We also have a speech and language therapist. Her role is reassuring as she provides tips on language and what to expect next. So that is our little team.

Over the last year, the focus on what we can do to help our child's language development has increased, but we've had access to a hearing impairment service the whole time. I can see that the staff are busy but they have provided good quality care and education for us. They have taught us about techniques to help our child develop English and BSL. It's been fantastic.

Where do you go for your BSL classes?

We're in a city that's got a school for the deaf. They run BSL classes but, unfortunately, only during the day when I have the children to look after. My husband and I decided very early on that we wanted to really embrace BSL and learn about it as fully as possible. We had to work very hard as a family to make it happen and we attend and pay privately for classes at our local college. We've done BSL level one, and now we're in our level two class. The woman who teaches us is profoundly deaf and is a 100% BSL user. She’s great and this immersion into BSL has been invaluable for us as learners. The class happens during our children's bedtime and we rely on friends and family to try and juggle everything. We actually ended up taking our son for the entirety of our level one course because he was breastfed. My mother played with him outside the college library and I fed him during the break. I think we just made it happen; we worked for it.

With regard to learning BSL, what advice and thoughts would you share with new parents who discover that their baby is deaf?

I would say that step one is learning from a deaf person. That is really helpful. Secondly, I think you have to be kind to yourself. BSL is a full language and learning it takes time; it's not an overnight game. We are having phases where we're better at incorporating BSL as a family than others. You have to find a way of starting to use BSL in your everyday life. Do you start with just labelling things? Do you just use sign-supported English? Do you use full BSL and BSL sentence structure? And If you do, how do you do that? There is lots of different advice and everyone has their own opinion. Probably the best thing that we’ve done was to listen to everyone, decide for ourselves, and act accordingly. I really enjoy learning BSL to be honest.

It is really important to know that BSL is different from Makaton. We have had lots of advice and suggestions about using Makaton, but I would really encourage people to find the right communication for them and their baby. There is a place for Makaton,[5] it is really good, but BSL is a full language and part of the child's Deaf identity. Learning BSL and embracing it as fully as possible is really valuable. Part of my role as a parent is to help advocate for my child, to help raise Deaf awareness within my community, and to help society understand that BSL is part of deaf culture.

I wanted to ask what might have made things better, but it almost sounds like not much

There is one thing - because the services have been very busy, we still do not know the cause of our son's deafness. We have a paediatrician who is great, but there is a long waiting list to access that service. As a result, my son is 15 months old now and we still don't know the cause of deafness. I don't know if we will ever know.

Until we were first seen by the paediatrician several months after diagnosis, I didn't realise that a diagnosis of deafness triggers multiple tests for other health conditions. It is good that they do that, but as the mummy in this situation, it is very intense. Is there a problem with the ear structure? Or is there a problem with the brain, heart, liver, kidneys? Oh, you name it, they test it. It would be lovely if you could just do this in a one-stop shop of every test all at once, but in reality the process is stretched out over a period of time. I don't necessarily know if there's a solution for that, but I have to juggle a lot of healthcare appointments.

I can tell that it is important for you to have a clear understanding about why your son is deaf.

Yes, that's right. From my perspective I want to understand everything about why my son

is deaf, partly so that I know what we're looking for or what we're up against, and partly so that we are knowledgeable. Knowledge is power, isn't it?

When we spoke before you mentioned a condition called cytomegalovirus (CMV)[6] that can cause deafness in babies. Can you say a bit more about that?

Yes, CMV is definitely worth mentioning because it is one of the leading causes of non-genetic deafness.[7] In fact it is the leading cause of non-genetic deafness across the world. CMV stands for cytomegalovirus. It is part of the herpes family and is closely related to chickenpox and mononucleosis (mono). In its simplest form, the symptoms are like a bad cold. Anybody can catch it but it is only usually a problem for those with a weakened immune system. However, If you are pregnant when you are exposed for the first time it can cause problems for the baby, including deafness.[8] I can see that CMV is affecting other families, but I do not know whether CMV has affected our family or not.

Given that there are steps you can take to prevent it, I think it is absolutely worth talking about. There is a higher risk of catching it if you have other young children or if you're working with young children. When I say it's preventable, it's preventable in the sense that you can reduce your risk of catching it by good hand hygiene and not sharing food with toddlers. I personally would recommend that this is listed with the things to be aware of in pregnancy such as not eating unpasteurised cheese and not cleaning out cat-litter trays. I am also anxious that midwives and doctors do not go to work when they have cold or virus symptoms. In this post-covid world we should all be really good at hand hygiene and not sharing food or doing things that might increase the risk of catching a bug, but actually we're not all the time. I just wish I'd known a bit more about this before I was pregnant. This virus might not have affected our life, but it might have. We will find that out in due course.

I know that your son was born at home and was not given antibiotics as a newborn, but when we spoke we mentioned the fact that the antibiotic gentamicin can cause babies with a particular genetic variant to become deaf. Scientists have recently developed a rapid test to identify vulnerable babies before treatment.[9]

Yes, the NICE guidelines (which are applicable to England) are very recent and I would be interested to know how widely across the UK this rapid testing is used. We need more research into understanding preventable causes of deafness. The Royal National Institute for Deaf People (RNID) charity is looking at research around the prevention and cure of deafness.[10] It's super important work and deserves all the funding and donations possible.

When we spoke together I was impressed by your positive and proactive approach to managing deafness in your family, but you have gone beyond concern for your own child, haven't you? Would you tell me about your plans for restarting a local Deaf Children's Society group?

Our son was diagnosed at the start of the school holidays and that meant that the teachers of the deaf were not available immediately. I was desperate to meet other people with deaf babies. I even did a very bizarre thing. We were on holiday and visiting a museum when I saw another child wearing hearing aids. I said to my husband, “That child's deaf”, and I creepily followed them around the museum a bit before plucking up the courage to approach this total stranger and introduce myself. That is so unlike me but I suppose it was a symptom of the need to connect with other families who are in a similar situation. So I started looking locally to try and find other people and over the past year or so we have found each other and are working together to restart the Grampian Deaf Children's Society.

The previous branch folded a year or so ago, probably around the time my child was born, but we could see that there was still a need for one. We are a powerhouse of parents who really want the best for their children. Together we share a whole range of skills and experiences. Everyone has their own very different experience of deafness and disability and their own stories. It's a total privilege for us to be able to work together, to collaborate, to make something happen for our local area.

We are just in the process of getting registered with OSCR (the Scottish Charity Regulator). Our vision is a multiple-fold one, providing support for other parents around the time of diagnosis; involvement with schools; and being a place where we can meet and talk. Collectively, as parents, we want our children to grow up, spend time and have a relationship with other children who wear hearing technology. That also goes for siblings who may be fed up with the family focus on hearing technology and the endless appointments. It's really important for them to have networks as well - to not be the only child that is in their situation. The group gives us a platform for providing peer support for each other, sharing knowledge, sharing education and developing various plans that will unfold over the next year. If you are in the Grampian area please look us up on Facebook Grampian Deaf Children's Society .

[1] Auditory Brainstem Response (ABR) test - information leaflet for parents (but not from Karrie's hospital) https://media.gosh.nhs.uk/documents/General_Auditory_brainstem_response_ABRKR_IOdGO4T_m8AujUa.pdf

[2] Editor's note: An audiogram is a graph that shows the result of a hearing test.

[3] Editor's note: Sensorineural hearing loss is usually caused by a condition of the inner ear affecting the auditory nerve - as opposed to conductive hearing loss where some obstruction prevents sound reaching the inner ear.

[4] Editor's note: Building a positive Deaf identity is considered vital for the child's development and self-esteem. https://www.ndcs.org.uk/information-and-support/parenting-and-family-life/emotional-health-and-wellbeing/supporting-your-childs-mental-health/building-positive-deaf-identity/

[5] Editor's note: It is worth mentioning that Makaton was developed for children with learning disabilities.

[6] NHS (2023) Cytomegalovirus (CMV) https://www.nhs.uk/conditions/cytomegalovirus-cmv/

[7] Korver AM, Smith RJ, Van Camp G, Schleiss MR, Bitner-Glindzicz MA, Lustig LR, Usami SI, Boudewyns AN. Congenital hearing loss. Nat Rev Dis Primers. 2017 Jan 12;3:16094. doi: 10.1038/nrdp.2016.94. PMID: 28079113; PMCID: PMC5675031. https://pmc.ncbi.nlm.nih.gov/articles/PMC5675031/

[8] CMV Action (2022) https://cmvaction.org.uk/

[9] NICE (2023) NICE recommends genetic test to prevent newborn babies going deaf https://www.nice.org.uk/news/articles/nice-recommends-genetic-test-to-prevent-newborn-babies-going-deaf

[10] Editor's note: While prevention and cure of deafness is considered to be an important goal for many hearing people, some other Deaf charities such as the British Deaf Association (BDA) campaign not for a 'cure' (as deafness isn't an illness) or prevention (they see it like preventing a baby being black or gay) but for full access and acceptance.

A child is born into the world and their world is in silence

By a hearing mother of a deaf baby

Author Bio: The author of this article lives in Wales and is remaining anonymous at the request of her son.

Image Source

I can share with you my experience as a hearing mother of a child who is deaf. I can only share *my* experience, not my child's and not another parent's because every story will have similarities and differences. I can share with you that finding out five weeks after our son's birth that he was deaf took me into a space full of questions, of shock, and most of all, to a different place from where I'd been with my son before I realised he couldn't hear. I had an immediate need to learn and to reach out to others in this situation. My very first question was to the audiologist asking how deaf our son was and whether we should learn sign language. The response to my question was no, see how it goes, it shouldn't be needed.

I'd been chatting and singing to our son, sharing my mother tongue with him throughout my pregnancy and after he was born, often communicating with him from across the room. What was my mother tongue to him now? Had I not been communicating with him in the way he'd needed me to? Had I done wrong by this? What contact with us had he missed? How were we meant to communicate now? How could I share a language with him that I didn't yet know? How could I find and show him his deaf world and community when I didn't know it and hadn't experienced it myself? Where was his deaf world? How strange that his world was different to mine. Did I need to be deaf to understand and provide for him in his world? Yet, as a mother, it is instinctive to share and show our own world to our child and to nurture them in a way that draws them into our world, but should I enter his world now, and how?

It is easier to enter a deaf child's world when a child is new and can be nurtured and loved for who they are; but predominantly we live in a hearing world. We rapidly learned that, in our society, a deaf child is steered into the hearing world. The hearing world does not enter and cultivate the beauty of a different silent experience; instead it very much lures a deaf child into hearing experiences, with a hearing language and a hearing culture. Pretty much from a few months old, with the fitting of our son's first hearing aids, the hearing world expected our son to adapt.

My inner yearnings were to run away from society and be in a peaceful wooded setting where my son and I could just be - at least for a while. Where I could love him for who he is.

Where we could communicate with the fundamental mother tongue that parents across the world and throughout history share - the language of love. A language deeper and beyond words that holds loving facial gestures and smiles, that creates bonds, nurtures with warmth and is a communication of meaning more than words. This image felt safe, it felt happy. Then, came the bombardments of appointments, long car journeys, continual assessments and the expectations that our son was meant to adapt into a hearing world.

Looking back now, thirteen years on, I can see what was missing in those early years. There was no-one to greet our son within his world. There was only a great clinical focus on how to draw our son into a hearing, listening, speaking environment.

One day, I was waiting for an appointment in a hospital waiting room and I glimpsed a doctor who I'd met before during the hospital stay after he was born. I felt a pang of pain as I had a flashback to the side wing of a hospital ward where this doctor, her eyes looking deep into mine, told me that my son had a bleed in his brain. She said that this would probably cause brain damage and that it was my fault. According to her, this was because my husband and I had decided that our son probably didn't need a vitamin K injection. It later turned out he had no bleeding and no brain damage, but as the conversation continued, and with the same deep stare, she repeated advice that we should allow them to treat our son with antibiotics. Again, we had decided as a family that, as there were no signs of infection, antibiotics were not required. We had declined antibiotics for the previous six days on that basis, but worn down by her accusatory tone we finally agreed to the antibiotic Gentamicin but with no knowledge or advice that it can cause deafness. Should I now, months on at his hearing appointment, stop this doctor, look deep into her eyes and inform her that our son is now deaf, probably from the antibiotics that she had so strongly advised?[1] Too late, she had walked past and I was left to deep breathe away my pain.

We consciously turned hospital visits into treats where we always bought ourselves a coffee out. The audiology staff listened to our wishes and decisions and met us with smiles. Over the months we watched our son learn every game with a growing commitment to join in with all that was asked of him.

His cheeky grins were complimented by everyone. But it was still not my happy safe place with our son. There is an element of sadness watching 'failing' tests, and while we responded with huge happy smiles to all his efforts, there was a sense we were needing to brave these constant assessments, wondering what positive difference they could actually make to a child that is deaf.

Despite the audiologist's advice we decided to learn British Sign Language (BSL) because we knew it is vital that deaf babies are exposed to sign language from birth.[2] This is for the very same reasons that hearing babies need to hear spoken language. Living in a rural part of Wales meant that reaching sign language lessons required my sister to drive for half an hour to our house to babysit our toddler and new baby while we drove for over an hour in a different direction to an evening lesson. By the time we had finished level 2 we had already paid hundreds of pounds each for these lessons, and level 3 was going to cost one thousand pounds each, which meant that, even with partial grant funding (that I had to seek out for myself), only one of us was able to attend. Only at level 6 do BSL learners come close to fluency. Most school teachers are below level 3. A high percentage of deaf children are born to parents that hear.[3] So, a very high percentage of deaf children receive little or no fluent role-modelling of their own language, at home or in school, leaving most deaf children unable to fully access full spoken language or full BSL. This adds to how deaf people are often migrating between a hearing and deaf world.

If we failed an exam, we had to wait for a re-sit the following year before we could continue to learn a language that our son needed immediately and a language we desperately needed to already know in order to share it with him. On the plus side we met an amazing deaf British Sign Language teacher who further introduced us to the deaf world and deaf culture. We also had a 'teacher of the deaf' and a speech and language therapist visit our house regularly. The teacher of the deaf was especially encouraging with our and our son's development in using BSL together as a family.

All the while we were on a journey of finding the deaf community in rural Wales. This involved a lot of emailing and long car journeys to any Deaf event, even to a coffee morning over an hour's drive away if someone attending used BSL. We discovered that a couple living up the road were both profoundly deaf. They went out of their way to sign with our son and they have since become good friends. We networked and eventually found an opening into the deaf world. Next came the decision about which primary school he would attend. It can apparently take two years to put everything into place, and it did. It took many meetings and almost went to a tribunal because the school with most deaf children was out of county. Our son made another huge adaptation and started to take an all round three hour taxi ride every day so that he could have school friends who were also deaf. Here he was able to grow up with friends who also signed until eventually we uprooted from friends and family support and moved to be closer to his school and his deaf community.

Deaf children are forced to adapt to a hearing world; it is inevitable, as we live in a hearing society. Some children undergo invasive surgery to have cochlear implants. This takes away their natural hearing and gives them 'electronic' hearing that their brain has to adapt to and learn to decipher.

The implant user then has to navigate the hearing world with different hearing, and often with total deafness on the occasions when they have to remove the external part of the device for activities such as swimming. Cochlear implants are not suitable for everyone and are not without risk. The pressure to take that option is a pressure to conform with hearing values, and some deaf people quite understandably resent this.[4] Other children manage through lip reading or using sign language, but in a world where the majority do not sign, the deaf child's Herculean effort to communicate is not rewarded with rich and meaningful responses from hearing people.[5] Even under the best conditions only about 30% to 40% of speech sounds can be lip-read and it is exhausting.[6] The deaf child is expected to make all these adaptations for the hearing world.

We have not even touched on how much a deaf child has to adapt in the education system when every test paper and exam is written in a language that is not BSL and when learning outcomes are assessed through written language rather than BSL.[7] There are many theories and philosophies about the education of deaf children, all of which have been debated throughout history and all of which have been reflected in the different trends within the education system.[3] A deaf child may fully adapt to the hearing world or may navigate between the deaf and hearing worlds, but the adaptation to the hearing world is one that every deaf child makes. Do we, as a hearing world, fully appreciate this?[8]

Returning to my memories of thirteen years ago - my desire to wander off from society and communicate with my son without the interruptions of society's expectations - the closest I got to actually feeling the gentle, happy, fun of just 'being' with my son (while also being 'in society') was on a family sign language weekend arranged by the National Deaf Children's Society. Run by a deaf signer, this was, unfortunately, a one-off weekend only. The very clear message of the weekend was to enjoy communication. Yes, we learned so much sign language, but the emphasis was on using obvious gestures, facial expression, eye contact and the joy of communication. It was a relief to the complication and struggle of the world of speaking, reading and writing. The deaf child's world of visual expressions and visual storytelling, the rich deep full language of BSL that paints meaning above and beyond the words that are signed, brought a wonderful sense of ease in moulding all of this together.

If I could wave a magic wand to resolve a mystery of how to comfortably merge two worlds together what would it be? I would ask for a warmer welcome to a deaf child newly born into the world.

I would ask that all practitioners working with a child in infancy, especially within an audiology setting and school, would gently and compassionately meet this young child in their (the child's) world, the world where there is silence; meet them and be with them, honour their beautiful and special place before pulling them into a hearing world with expectations, tests, equipment, technology and all the other areas of learning and adaptations that will inevitably follow all too soon. First greet the deaf baby and child warmly with other deaf people involved in their care from the start.

Where was the welcoming from a deaf person as our son first entered audiology? Our son has never seen anyone using sign language in audiology in the thirteen years he's been attending. He entered through the school gates on his very first day at school and he was met with warm smiles and sign language, but where were the deaf adults that understood what he was experiencing? Where were the deaf people that live in his world with him and have to make huge adjustments daily for all those living around them, just as he has to? Where was the deaf teacher that will understand how a deaf child's full capable mind will inevitably learn in different ways?[3] Where were his deaf role models?

Our BSL teacher once told us that as a child he waited in his classroom excited to meet his new ‘teacher of the deaf’. At last he was going to meet a deaf teacher, a teacher who will understand. Like many other deaf children, his parents were hearing[3] and he had never met any member of staff in any hospital or education setting who was deaf like himself. He waited with excited anticipation and then she entered the room and, once again, she was hearing.

Deaf children and adults often find themselves stepping in and out of two worlds wondering where they belong. I urge the NHS, local authorities, schools and councils to train and employ deaf people - this could be literally world-changing for deaf babies and children and for their parents.

[1] Editor’s note: Some people have a gene that can result in deafness when they are exposed to the antibiotic gentamicin. Premature babies are particularly susceptible. A rapid test for this gene has only very recently been developed. https://rnid.org.uk/2022/04/new-test-could-save-the-hearing-of-hundreds-of-babies-a-year

[2] MAYBERRY RI. When timing is everything: Age of first-language acquisition effects on second-language learning. *Applied Psycholinguistics*. 2007;28(3):537-549. doi:10.1017/S0142716407070294 www.cambridge.org/core/journals/applied-psycholinguistics/article/when-timing-is-everything-age-of-firstlanguage-acquisition-effects-on-secondlanguage-learning/3B1A8327FF0E7926F858FE995BEC3074

[3] Terry J. Enablers and barriers for hearing parents with deaf children: Experiences of parents and workers in Wales, UK. Health Expect. 2023 Dec;26(6):2666-2683. doi: 10.1111/hex.13864. Epub 2023 Sep 11. PMID: 37694502; PMCID: PMC10632626. www.ncbi.nlm.nih.gov/pmc/articles/PMC10632626

[4] Chapman M, Dammeyer J. The Relationship Between Cochlear Implants and Deaf Identity. Am Ann Deaf. 2017;162(4):319-332. doi: 10.1353/aad.2017.0030. PMID: 29129834.

[5] Marschark, M., & Hauser, P. C. (2012). How deaf children learn: What parents and teachers need to know. Oxford University Press

[6] National Deaf Children’s Society (2024) Lip-reading www.ndcs.org.uk/information-and-support/language-and-communication/spoken-language/lip-reading

[7] Editor’s note: BSL is not signed English, it is a different, visual language, with its own grammar. Used from birth it enables the deaf child to communicate and to develop their capacity for language. English is then a second language. It is a sound-based language that the deaf child has never been, and can never be, immersed in and acquire naturally. School exams and tests offered only in English automatically disadvantage the deaf child.

[8] Editor’s note: This is such a brilliant question - and the answer is, no we don’t. We probably think that we have a duty to ‘fix’ deafness and to ‘help’ the deaf child to integrate. But what if we imagined a world where diversity was recognised and we knew it was *normal* to have deaf and hearing people, a world where we all grew up bi-lingual from birth (or at least from nursery school), a world where visual, tactile and sound communication was automatically available in all situations - simply because this was the normal thing to do? Only then might we start to see some equity for deaf people.

Welcome to the Deaf Community – a lesson in miscommunication to new (hearing) parents

by a hearing mother of a deaf baby

Author Bio: This mother has chosen to remain anonymous.

Image Source

Sat in the hospital ward, I snapped a cute picture on my phone of my tiny little newborn wearing a headset, with nothing on my mind other than “Aw, he looks like a tiny DJ.” I had no idea that we were starting on a journey that I had absolutely no preparation for. The lady doing the hearing assessment kept shaking her head, but on this newest of days, my baby’s very first day in the world, there was no real communication on what ‘failing’ the test meant. It felt relaxed. I was exhausted. And he really did look cute.

“The hearing equipment can play up a lot, I’ll just come over again later.” I didn’t even react, just staring into my little best mate’s hiccupping face.

When she came back, the story was the same, although this time I did feel a little more anxious. It had been a traumatic birth for both of us and I was worried his slightly dramatic entrance had done damage. Even then, that was brushed off, “Ah that will be it! The water in the birthing pool/the ventouse/the surgery…”. Goodness, it had really been a whirlwind 24 hours. The headset just must be wrong. Right? Looking back, the reassurance and stoic ‘all is well’ is probably a natural response from those operating the tests, designed to stop any unnecessary panicking, but some simple and matter-of-fact facts at this stage would go a long way. The next stage of testing gets thrust upon you so fast as a parent you feel completely blindsided. More on that later.

When we checked out of the hospital, we were told that we had to be at a hearing test at an audiology unit within a certain time of the birth - and our appointment was the very next day. Knowing what I know now – WAY too soon. It felt a big deal to trek into town to the audiology unit with my tiny baby when all I wanted to do was rest and recover. I was not ok post the birth and I remember the pain trying to walk from the car park nearby as if it was yesterday. I hadn't realised at that point that I was also at the start of a severe infection (another story for another time..)

The tests were in a boiling hot room. I'd forgotten to wear buttons (I'd not been a breastfeeding parent before – to be honest I was still struggling with that bit). This part is a total blur in my mind: I remember not really understanding anything at all, or being told information in any clear way to guide us through. The audiologist just kept saying the word 'deaf' and then being irritated with me for not being able to soothe my baby by feeding in the room. I had to take my dress off to feed him. It was absolutely awful. I remember stickers and glue that ripped my baby's hair out…and I remember the sobbing…his and mine.

We didn't get an accurate test as the little one couldn't relax, which was not surprising. We were going to have to do it all again. We still didn't really know what 'it' was.
A couple of weeks later, I was still so uninformed about this process that I thought it was ok to go back to the audiology unit, this time without my husband. A huge, huge mistake to have gone alone.

I was in a boiling hot, unventilated room for what I think was five – six hours (again, a blur) whilst they glued probes to a tiny head. No one offered me (a breastfeeding new mother) any refreshments or a break. It felt like I had to stay until we 'got this done' and the determination from the audiologist felt, on reflection, brutal on me - on the baby in my arms - and bordering on the inhumane.

I was completely upset and confused by the end of the testing and was handed a 'welcome to the deaf community' leaflet with a grin that was inappropriate and mistimed given my lack of time to process the news I was being given.

It was pouring with rain outside as I fumbled my way out of the clinic – leaving my phone behind. I went back in and, trying to maintain some sort of normality in my voice, joked "you'd think I'd have been desperate to get out of here". The audiologist. without irony (or a drop of empathy). quipped "well, hahahaha, get used to it, you'll be here all the time!” My panic escalated – was this prodding, poking, distressful process going to be routine? I was angry as I got back to the car park charge for six hours of parking. I should not have been on my own. I should not have been there that long with no food or drinks. The appointment letter had never specified the length of time that would take, or any outline of the appointment’s details. And I was reeling – my little boy was deaf? What did this even mean?

My husband provided comfort with ‘not THAT deaf’ as he understood more clearly the ‘mild to moderate’ range that our son was hearing. Not one professional had even attempted to define it for me at the hospital.

The next days were spent scrolling through research and with an avalanche in my head of trying to find blame, trying to find a counter diagnosis, trying to find the best experts in the world to tell me that this news was wrong, or inaccurate. I phoned experts, I googled international audiology departments, I read papers on paediatric deafness and I desperately didn’t want this to be true. I was also convinced this was my fault: The ‘hen do’ I went on before I realised I was pregnant? The hot tub I went in at a spa? The time I had slipped off an office chair at work? The thoughts whirred and whirred constantly and the 3am feeds were not the only thing keeping me up. I had done something wrong. Thinking this way was unfair, and actually I am ashamed of my prejudice at this point. This was my little boy’s reality and he was perfect. A beautiful, good friend shook sense into me with the words “Stop it now. This is just his ‘thing’. We all have one and this is no more special than others.” It was what I needed to hear and to this day is exactly right. It stopped me trying to somehow ‘solve it’ and it helped me get on with the next steps. Some simple communication from the experts at this early stage would have stopped this spiralling and worry. It was never offered.

A test for cytomegalovirus (CMV) was terrifying. If you haven’t heard of it (I had not) it’s a virus that can be picked up by pregnant women when dealing with children’s nappies/mucus from noses etc. Being deaf can be a consequence for the baby if the mother caught CMV during pregnancy. I hadn’t heard of it. I googled it and was petrified waiting for the results.

A kind Irish surgeon called my phone at 9pm on a Sunday night and told me it was not the cause. The relief. But still, the questions.

We did test after test over the coming weeks (or was it months?) and I felt like I lived in the hospital, constantly lost as I toured different departments to have my tiny newborn examined. It was exhausting, and again, the communications were so poor. I often arrived for appointments with absolutely no explanation of why or what they were for!

When I questioned the need for aids, I got different versions of the fact it was the only way forward for him, with one consultant bluntly saying “It’s the difference between him growing up to have my job, or becoming a plumber.” I like plumbers! I really wasn’t taking her clumsy point onboard for what she was trying to explain. And still I kept trying to find out how I had ‘damaged’ my child.

Eventually, it was a clear diagnosis – it was bi-lateral, sensorineural moderate hearing loss with no other related issues. It would be about two years until we were told that this was a genetic condition inherited from both of us as parents who had a mutation on the cx26 gene. I actually have two! So, it was my fault, after all. But it was not in my control. My son got his hearing aids at ten weeks old. It wasn’t like the dramatic videos you see. Again, the confusion for me was understanding the diagnosis for his level of hearing loss. He could hear and was responsive – he just didn’t hear very well. I watched him like a hawk, not trusting in the process at all as at no point did I feel I got the answers I wanted.

Is this hurting him?
Could they have got the setting wrong?
Is he really deaf?
What does he actually hear?
Has this changed his perception of my voice –
his own mummy’s voice?
Is everything robotic/digital?

Endless.

I made it a mission to learn everything I possibly could about the condition, his hearing loss levels, and the technology. I Looked in depth at the specific make of the technology my son was using and I contacted the experts from that company. I was initially seeking alternative answers but really, I ended up with a profound reassurance that we were doing the best we possibly could for our son - that this technology now is the most advanced it’s been for generations - that it was going to get better for him as he ages.

This has led me on a quest to try and put that reassurance in the hands of parents at the start of their journey. I don’t want any mum or dad to doubt their decisions in taking advice, but I do want those advising to be better at it. I think the professionals need to take a step back and, rather than thrusting ‘welcome to the deaf community’ leaflets at terrified parents, find a way instead to show that they care. This could be achieved by *really* listening to the parents, by having good clear information to hand, and by being able to help the parents feel confident that aiding your baby is one way of helping them fulfil their potential.

My little boy is doing so well at five years old – I wish I could have met him in that hospital ward on that day of diagnosis and hear his clear speech, his interaction with others, his jokes, his singing, his creativity and his joy. Because I needed to see an example of what this was going to look like and no one seemed to be able to give that story to me. I have so many learnings from this experience – and probably could write fifty blogs on how new challenges present every day. But honestly, the hardest part was those early months and the way that there was so little communication, or evidence, or reassurance. The lack of empathy from supposed ‘experts in their field’ was unnecessarily distressing and at times woefully careless. However, those same experts are doing a great job by my little boy, proven by his development and abilities.

So, in summary, whilst the ineptitude of the system leaves you feeling bereft of information, I would offer any new parent these reassurances: that the audiology teams will help your child; the technology can be incredible; the opportunities for your baby are limitless; you have the right to ask questions and get clear answers; you can give yourselves time to reflect; and you can trust yourself to make the right decisions. My plea is for audiology units to ensure that their communication with and handling of parents in those early days are done with more empathy and expertise.

Pregnancy and hearing: Did you know?

By Alex Smith

Author Bio: Alex Smith is a long-time childbirth educator, editor of the AIMS journal, and the grandmother of a profoundly deaf

Image Source

- Did you know that one in three pregnant women develop tinnitus compared with one in ten who are not pregnant? Tinnitus is the sensation of buzzing, ringing or whooshing noises in the ear. It may be a sign of high blood pressure and possibly an early sign of pre-eclampsia, but it may also simply be due to the effect of the physical changes of pregnancy.
- Did you know that pregnancy can trigger or worsen hearing loss? This is surprisingly common with one small study in India seeing it in almost 5% of the 379 pregnant women who attended their hospital that year.[1] There are different reasons for hearing loss with most being temporary but some being permanent. It usually occurs in the second or third trimester or even after the birth, and can be unilateral or bilateral, conductive or sensorineural.[2] Sudden sensorineural hearing loss (SSNHL) is relatively rare but is considered to be a medical emergency. Apparently the incidence of this has increased with rates varying between 2.7 in 100,000 in Taiwan, 27 in 100,000 in America and 160 in 100,000 in Germany.[3] When I asked on a Facebook group for deaf and hard of hearing people about people's experience of maternity care, three of the small group who replied had experienced a deterioration in their hearing, with two saying that no one could tell them why.
- Did you know that Deaf and hard of hearing women are often asked to remove their glasses and hearing aids when they go for a caesarean. Two responders from my Facebook question experienced this. One woman wrote:

"Had my emergency C-section four years ago and they made me take off my glasses and hearing aids. I felt so helpless."

"So four years later I had an elective C-section and strongly requested for my glasses and hearing aids to be kept in and they agreed. I felt so much more comfortable."

There is a rationale for removing these aids, but clearly it is also possible to accommodate them, so why not anticipate that a Deaf woman may want to see and hear her baby's first cry.

- Did you know that the antibiotic gentamicin can cause deafness in susceptible babies? It is commonly used to treat premature babies and for a long time it was assumed that the subsequent deafness was caused by the prematurity rather than by the medication. These drugs are often given while awaiting a confirmation of infection and may not even have been required. A new rapid test is available so that vulnerable babies can be identified before starting treatment.
- Did you know that Deaf people are twice as likely to experience trauma in their lives as hearing people? In this very interesting study from the States,[4] Deaf participants reported similar trauma experiences to the hearing population but the details of those experiences were different. For example, both deaf and hearing people may find themselves in an abusive relationship, but deaf people are more likely to remain in one if their partner is the only person they can communicate with. The ability to communicate seems to override safety. This is reflected in the fact that many deaf people will avoid seeking medical care because their communication needs are not met. In addition, deaf people are constantly subjected to audism and linguisticism,[5] which are forms of oppression-based trauma. Common themes found to be protective in relation to resilience in these situations included: individual assets, identity development, access to language and communication, access to information, and supportive networks. As over 90% of deaf babies are born to hearing parents, it seems that the very least the Government could do would be to provide excellent quality, accessible and free BSL classes for the new parents - ideally taught by someone who is also deaf who could then be a bridge between the family and the support of the Deaf community, and also be a positive role model for the child. This would pay dividends in the long term.
- Did you know that, *as far as I know*, there are no Deaf doulas in the UK; none that use BSL as a first language and offer support to Deaf families. In the States they have the wonderful Hand Waves Birth Services. This video shows the difference it can make to have someone with you who speaks your language.

[1] Swain SK, Pati BK, Mohanty JN. Otological manifestations in pregnant women - A study at a tertiary care hospital of eastern India. J Otol. 2020 Sep;15(3):103-106. doi: 10.1016/j.joto.2019.11.003. Epub 2019 Nov 22. Erratum in: J Otol. 2020 Dec;15(4):179. doi: 10.1016/j.joto.2020.09.006. PMID: 32884561; PMCID: PMC7452357.

[2] Editor’s note: Sensorineural hearing loss results from damage to the hair cells within the inner ear, the auditory nerve, or the brain's central processing centres. Conductive hearing loss results from the inability of sound waves to reach the inner ear.

[3] Xie S, Wu X. Clinical management and progress in sudden sensorineural hearing loss during pregnancy. Journal of International Medical Research. 2020;48(2). doi:10.1177/0300060519870718

[4] Paige Johnson, Stephanie Cawthon, Bentley Fink, Erica Wendel, Sarah Schoffstall, Trauma and Resilience Among Deaf Individuals, The Journal of Deaf Studies and Deaf Education, Volume 23, Issue 4, October 2018, Pages 317–330, https://doi.org/10.1093/deafed/eny024

[5] Editor’s note: Audism is the belief that being deaf is a physical flaw that needs to be repaired in order to live a full and rewarding life. Linguisticism is the superior regard of one cultural language over the other, for example, English over Sign Language.

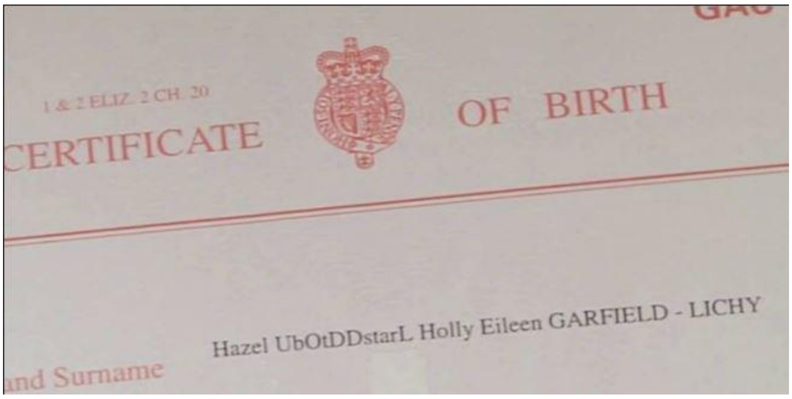
The BSL Birth Certificate

by Salli Ward

Tom, and his and Paula’s daughter, Hazel (sign name ‘big smile’)

Author Bio: Salli is mother/stepmother to 8 grown-up children and Nana to 3. She has been a dramatherapist, a charity CEO, a celebrant, a fundraiser and writer. Having worked with and for Deaf charities for many years, she is a less-than-fluent-but-okay BSL-user with a good understanding of Deaf heritage, culture and campaigning.

When Tom Lichy and his partner Paula Garfield had their second baby, they wanted her BSL name to feature on her birth certificate as BSL was their first/preferred language. There is a way to notate movements of a signed language, and the parents first consulted a linguist to help. The bigger fight was a legal one, but they eventually won and their daughter, Hazel UbOtDDstarL Holly Eileen Garfield-Lichy was registered as just that.



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and Surname Hazel UbOtDDstarL Holly Eileen GARFIELD - LICHY

The BSL name can be translated as something like ‘big smile’ in English but that’s not how signed names work – they can’t really be translated, just as many names in other languages can’t. Sign names are often visual, referring in some way to how a person looks (my BSL name indicates my usual hairstyle of one plait) but Tom and Paula chose a quality of their baby’s personality.

These days the BSL Act 2022 gives Deaf people greater rights than back in 2013 when the birth certificate battle was won; however, many institutions still deny BSL-users full access and campaigning goes on.

AIMS Physiology-Informed Maternity Services (PIMS) - December 2024

Update by Catharine Hart

Author Bio: Catharine Hart studied biology at the University of York and later trained as a midwife at the University of East Anglia. Catharine is currently a full-time mum, which she combines with her volunteer role at AIMS, working in the Campaigns Team. She lives with her family in Suffolk.

In this piece Catharine Hart reports on the Microbirth Summit. The information she shares, while very interesting, may be challenging for some people and may raise questions for others. For example, in order to make a fully informed decision, the AIMS reader may want to know more about the risk/benefit balance of practices thought to promote a healthy infant microbiome, compared with practices thought to compromise it; they may want to know more about what constitutes a healthy microbiome and what evidence we have for this; and they may simply want to know (with helpful numbers) whether or not microbiomes really matter that much. Please read this report as a starting point for those questions, and look out for more on this topic in future issues. If you would like to share your thoughts on this topic, suggest ways in which this area of knowledge is likely to improve our maternity services, or tell us about anything you are doing or have seen being done to make such improvements, please contact me, the editor, at alex.smith@aims.org.uk.

In July, I attended a two week online microbirth summit hosted by Toni Harman (producer and director of the 2014 film *Microbirth* and founder of the microbirth school[1]). The summit had presentations from this year's Microbirth virtual conference and live question and answer sessions.

The microbiome is a developing area of science and I found it absolutely fascinating to learn more about it. Some of the information that was shared just totally blew my mind -

for example, we were told that there are more microbes inside our bodies than human cells - an estimated 38 trillion microbes, compared to ‘only’ around 30 trillion of our own cells!?

We started with a simple introduction. What is the human microbiome? It is simply a community of microorganisms (bacteria, archaea, protists, viruses or fungi) which live on or in the human body.[1] The two main microbiomes talked about in terms of maternity are usually the infant skin and gut microbiomes.

The microbiome is usually found in areas of the body which connect to the external environment, such as the skin, mouth and gut, which can also be entry points for infection. If there is a healthy microbiome, this can give more resistance to disease-causing microbes gaining a hold, preventing potentially serious infections. A healthy microbiome is thought to be really important for long term healthy development and for giving protection against some chronic diseases. Both *seeding* (colonising) and *feeding* the microbiome help to establish a healthy microbiome in newborn babies. Seeding usually happens when microbes are transferred during vaginal birth (from the mother’s vagina and gut), during skin-to-skin contact and some microbes can also seed from breastmilk. Breast milk is also helpful for feeding the newborn’s gut microbiome as it contains unique carbohydrates - human milk oligosaccharide sugars (HMOs) - which gut microbes feed on - in fact these sugars cannot be digested by human cells at all. We heard that there are certain skin microbes that are typical of the infant or maternal skin, and microbes that are associated with the mode of delivery (babies born by caesarean section typically have a different microbiome from babies born vaginally). If the baby’s skin is not colonised by the mother’s microbiome, it is much more likely to be colonised by other bacteria instead, which could include potentially disease-causing hospital bacteria if the baby is in hospital, for example.

Dr Nils Bergmann talked about Kangaroo Mother Care. First developed as an alternative to incubator care for low weight or preterm infants, Kangaroo Mother Care is usually defined as prolonged skin-to-skin contact, breastfeeding and early discharge home from hospital.[2, 3] However, according to UNICEF the importance of skin-to-skin contact immediately after birth applies to all babies for a number of reasons, only one of which is the microbiome. Establishing an emotional connection through skin-to-skin contact can also create feelings of trust and safety - rewiring both the baby’s and mother’s brain. The World Health Organization Baby Friendly Initiative promotes at least one hour of skin-to-skin contact following birth,[4] but Dr Bergmann emphasised that this should really last at least six hours for the baby and 20 hours for the mother’s sake,[5] in terms of optimum brain rewiring.

With the aim of preventing later-onset chronic diseases. Dr Katri Korpela discussed possible ways of restoring a healthy microbiome in situations where colonisation may have been disrupted. These situations include caesarean birth, exposure to antibiotics, or a lack of breastfeeding. Various ways of doing this as safely as possible have been studied, including giving probiotics alongside exclusive breastfeeding. Exclusive breastfeeding alone for babies born by caesarean section provides some microbes, but not enough for a full seeding, compared with vaginal birth. There have been some studies into faecal microbiota transplantation (using microbes from the mother's poo). In theory this can restore a normal infant gut microbiome, but because of possible pathogens not everyone is considered to be eligible for this and some may also not find it very acceptable. Seeding from a vaginal swab only partially restores the infant's gut microbiome because the vagina does not contain the main gut microbes, in fact in healthy women it is a deliberately hostile environment for them.

We heard that the immediate period after birth presents opportunities for adopting approaches to care that promote the normal establishment of the microbiome. Dr Michelle Irving discussed this and pointed out that postnatal care is often based on custom that has not been updated to reflect recent evidence about the microbiome, e.g. removing babies from the mother for routine procedures, which can disrupt the normal microbiome colonisation. We discussed ideas for lots of simple changes to care practices, which could help to prevent this disruption, at very little or no cost. It's important that birthworkers have access to up-to-date evidence about this topic and feel confident to deliver physiology-informed care at every birth, even when medical assistance is also welcome. Working with, rather than undermining, salutogenic processes,[6] for example, by offering women and birthing people the option to bring in their own towels or pillows from home to a hospital or birthing unit, postponing bathing the newborn or offering parents the option to put their own baby on the scales for weighing, maximises the baby's contact with the healthy family microbiome.

We also heard about responsive breastfeeding, how it involves responding to the baby's cues, recognising that feeds are not just for nutrition, but also for love, comfort and reassurance. This, we were told, secures optimal nutrition, immune system development, attachment and the development of positive feeding habits well into infancy. There was also a session on infant massage and how it can help support the infant microbiome by increasing skin colonisation, decreasing cortisol and increasing oxytocin levels.

Overall, the summit offered a fascinating series of sessions, which AIMS is reflecting on,[7] with the aim of developing a case study for our physiology informed maternity services campaign.

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Please also see AIMS recent Evidence Submission to the House of Lords Preterm Birth Committee. www.aims.org.uk/campaigning/item/evidence-preterm-birth#ref23

[4] UNICEF (2024) Skin-to-skin contact Skin-to-skin contact - Baby Friendly Initiative

[5] Editor's note: These figures are in line with the World Health Organization's recommended 8-24 hours of skin to skin contact every day for small or premature babies. www.who.int/news/item/16-05-2023-new-resources-released-to-help-more-preterm-and-low-birthweight-babies-benefit-from-kangaroo-mother-care

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Please also see AIMS journal issue on Salutogenesis: www.aims.org.uk/journal/item/editorial-salutogenesis

[7] Editor's note: Reflection rather than immediate endorsement. or querying of unfolding knowledge and ideas. is important to AIMS.

Birth Activists Briefing: Maternal Mental Health Service Progress Report

By the AIMS Campaigns Team

The NHS England Long Term Plan published in 2019 called for the establishment of ‘maternity outreach clinics’, now known as maternal mental health services (MMHS), across the country. This was a welcome initiative, intended to redress the long-standing neglect of perinatal mental health. The aim was for MMHS to support women with moderate to severe mental health conditions directly related to their pregnancy experience, through three “pathways of care” (as quoted in the report):

- Birth trauma
- Tokophobia (severe fear of childbirth)
- Perinatal loss, including miscarriage, stillbirth, neonatal death, medical termination of pregnancy and parent-infant separation at or soon after birth due to safeguarding.

They were also intended to provide training to other healthcare staff and help to facilitate joined up mental health care across the maternity services in their area. This Maternal Mental Health Services progress report published in October 2024 by the Maternal Mental Health Alliance (MMHA) reveals that, although services have been established in most areas, there is wide variation in the extent and quality of provision. Further, “many of these small services are struggling to cope with levels of demand.” It seems that perinatal mental health remains seriously underfunded and under-resourced.

An interim report ESMI-III: The Effectiveness and Implementation of Maternal Mental Health Services was published by the National Institute for Health and Care Research in 2022 but as the MMHA report notes “this does not include detailed information such as locations, staffing levels, pathways available and common challenges faced by teams.” It is this gap that the MMHA report sought to address. Their research took the form of an online questionnaire to which replies were received from 41 out of a possible 46 services. Worryingly, one service had already closed due to funding issues.

All the services that replied are offering support to women who have experienced perinatal loss, but only 85% are supporting those who have experienced birth trauma and only 80% those suffering tokophobia. Even more troubling, given the vulnerability of this group, is that only 27% (11/41) are supporting women who have lost custody of their babies due to safeguarding concerns.

The MMHA report also notes that “the wide variation between services: what care is provided; what the criteria are to access care; and how long women must wait, suggests there are not enough resources to meet the true needs of the population.” As a result there is a postcode lottery in whether women and birthing people with similar needs qualify for support or receive it in a timely manner. The waiting time for assessment ranged from ‘immediately’ up to six months, and the wait for one-to-one therapy could be up to a year in some areas. The damage being done to the mental health of mothers and families by these lengthy waits, or by being referred and then told they do not qualify for treatment, is appalling to contemplate.

Although most services have funding assured for their current level of provision this does not allow for expansion, despite there being unmet demand. Many are also struggling to recruit and retain the staff they need.

Another concern highlighted in the MMHA report is the failure by a high proportion of MMHS to collect data on which population groups are accessing their services and, in particular, data on those likely to experience greater discrimination. Without this, attempts to improve equity in access to maternal mental health services are likely to fail.

The MMHA make the following recommendations:

- Commitment to MMHS at national and local level, with ongoing targets and clear expectations of what the MMHS offer should be
- Expand MMHS to meet levels of need, with a clear timeframe
- Make MMHS inclusive for all, ensuring that they are “resourced to reach out, become more culturally inclusive and adapt to the unique needs of their diverse local communities.”
- Collect and publish more data to demonstrate progress and gaps
- Quality standards for MMHS to deliver “compassionate and equitable treatment.”
- Education and training across the system with sufficient time allocated for MMHS staff to provide this.

These are all worthy aims, but fundamentally what is needed is a commitment to resource MMHS to meet the needs of all who need it, so that “ALL women, babies and families impacted by perinatal mental health problems have equitable access to high quality, compassionate care and support.”

How does midwife continuity of care compare with other models of care?

By Catharine Hart

Author Bio: Catharine Hart studied biology at the University of York and later trained as a midwife at the University of East Anglia. Catharine is currently a full-time mum, which she combines with her volunteer role at AIMS, working in the Campaigns Team. She lives with her family in Suffolk.

In this report, Catharine Hart of the AIMS Campaigns Team, tells us about a recent Cochrane study that was asking the same question.

Cochrane review: Midwife continuity of care models versus other models of care for **childbearing women (2024)**

What is it: A review of 17 randomised controlled trials that compare outcomes for women and babies who received midwife continuity of care with other models of care. This review was first published in 2004 and previously updated in 2016.

Who published it: The Cochrane Library

Publication date: 10 April 2024

Key points: This review compares outcomes for women and babies who had midwife-led continuity of care[1] with other models of care, such as obstetrician-led or shared care.

Please note that this review is looking at midwifery continuity of *care*, rather than continuity of carer.

(See also our AIMS comment below).
The authors define midwifery continuity of care as care that is provided by the same midwife or team of midwives. This can be through caseload midwifery (where women have a primary midwife assigned to them, with a backup midwife) or team midwifery (where a team of midwives share a caseload, usually between 6 and 12 midwives).[2] Within all of these models of care, care is provided in conjunction with medical staff as needed.

This review is a meta-analysis of 17 different studies, looking at a wide range of outcomes for 18,532 women and babies, over a variety of settings spanning five countries (Australia, Canada, China, Ireland and the UK). The majority of studies (12) were based on team midwifery, with 5 looking at caseload midwifery. The authors searched databases for new studies to include since the last update, adding three new studies and removing one study that was previously included. The authors assessed whether each study was at risk of bias and estimated the certainty of each of their findings.

The authors found that women who received midwife continuity of care were more likely to have a spontaneous vaginal birth (70% compared with 66%) and slightly less likely to have a caesarean or instrumental birth, both reduced by 1%, or an episiotomy. It wasn’t recorded whether women in the continuity group had fewer caesarean births because of reductions in the number of elective or emergency caesarean sections. The authors also found that continuity models offered cost savings in the antenatal and intrapartum (during labour and birth) periods.

Although women in the continuity group appeared to have a much higher chance of having a known midwife at their birth (63-98%) compared with those under other models of care (0.3-21%), there were wide variations in these figures and much of the evidence was considered to be poor or at risk of bias. The researchers therefore decided that, statistically, there was no strong evidence that women in the continuity group were more likely to have a known midwife at their birth.

Although the risk of adverse events appeared to be similar for women and babies in both groups, the authors state that this is slightly uncertain because of the “risk of bias, inconsistency, and imprecision of some estimates”. The authors found that midwifery continuity of care had little or no effect on the chances of preterm birth, induction of labour, admission to neonatal intensive care or having an intact perineum (not tearing) during vaginal birth. The authors found that continuity also seemed to have no effect on the chance of having a postpartum haemorrhage, initiating breastfeeding or having a low birth weight baby, although the evidence around these outcomes is less certain.

The authors felt there wasn't enough evidence to say whether midwifery continuity of care had any effect on the chance of miscarriage, having a third or fourth degree tear, regional anaesthesia (such as epidural), stillbirth or neonatal death. It is difficult to assess the impact of continuity on rarer outcomes, such as stillbirth, as much larger studies would be needed for reliable results.[3]

AIMS is glad to see that women's experiences were counted as one of the outcomes in this review. The authors acknowledge the problems of trying to measure these experiences quantitatively, so describe them narratively instead. Women who experienced midwife continuity of care reported more positive experiences - including satisfaction with the location of their care, number of visits, relationship with their healthcare provider, choices and decision-making. The authors conclude that, overall, women allocated continuity "showed higher levels and better experiences across measures of trust, safety, quality of care, support, bonding, and physical health postnatally".[4] These results are echoed by other studies which show that women who have continuity of care or carer usually report higher levels of satisfaction with their care.[5]

Several of these results represent a significant change in the evidence around midwifery continuity of care. For example, the previous version of this review found that women with midwifery continuity of care were less likely to experience miscarriage, preterm birth or regional anaesthesia.[6] One of the studies newly added to this review which looked at women with specific risk factors for preterm birth did not show a reduction in preterm birth for women having continuity of care, which changed the conclusions about the effect of continuity of care on preterm birth. One possible limitation of this review is that it included both team midwifery and caseload models, which may have different effects. For example, although the authors found no statistical differences in preterm birth rates between women under caseload or team midwifery within the studies included in this review, results from other studies suggest that caseloading models can reduce preterm birth,[7, 8] The LEAP (Lambeth Early Action Partnership) study, for example, found that women allocated caseload midwifery had less than half the rate of preterm birth (5.1% vs 11.2%), compared with women receiving standard care.[7] Of the seventeen studies in this review, the vast majority also only looked at hospital birth settings, with five studies including birth centres and only one including homebirth, so these findings may not apply to settings outside of hospital, especially homebirth. Although the majority of participants were classed as low risk, two of the three newly included studies looked at women with specific risk factors for preterm birth and depression. This could mean the results can't all be generalised to low risk women. Although the authors note that women with continuity may have "greater agency.... enhanced co-ordination or navigation of care, greater advocacy, timely follow-up of test results, and greater adherence to treatments",[4] they also acknowledge that we don't really know how continuity of midwifery care improves outcomes for women and babies,[9] stating that it is a "complex intervention". It is especially challenging to think about this when the different models of care being studied are not always standardised.[10]

Earlier versions of this review have been called "groundbreaking"[11] for providing solid evidence in support of midwifery continuity models of care. However, randomised controlled trials also have limitations, as discussed more fully on our AIMS webpage Understanding quantitative research evidence .[3] One of these is that usually only short term outcomes are measured, so we can't know whether continuity of midwifery care affects longer term outcomes. Unfortunately, there was also no data available for some important outcomes, such as whether mothers or babies were healthy after birth or babies were readmitted to hospital, despite the authors initially hoping these outcomes would be included. Some of the outcomes may not give a true indication of the quality of care if taken by themselves. For example, there may be many reasons for variations in caesarean section rates between different units and this measure is no longer recommended to compare the performance of UK hospitals.[12] While AIMS applauds the Cochrane collaboration's aim to "provide accessible, credible information to support informed decision-making",[13] individual women and birthing people may also want to know about other outcomes which are not covered here, such as breastfeeding continuation rates. The Albany caseloading midwifery practice, for example, had much higher rates of breastfeeding continuation than the UK national average.[14]

The authors acknowledge that some of the results were at risk of bias; for example, in a few of the studies people assessing the outcomes were not blinded as to which group the participants were in. In some trials the option of using a midwife led birth centre was only available to those in the continuity group, which could have altered the results, as birth setting can affect many of the outcomes measured.[5]

The authors also acknowledge that more research on diverse study populations is very much needed, to improve our understanding of the effects of continuity, especially for those most at risk of the poorest outcomes. Many of the studies excluded high risk or socially disadvantaged women, so the findings may not apply to them. The authors recommend more research is undertaken specifically looking at women with social risk factors or medical complications, especially as they may benefit most from midwifery continuity of care.[15]

Overall, this is an important review which provides reliable evidence to support the continuing implementation of midwifery-led continuity of care models in the UK. Despite the fact that continuity of midwifery care has been a UK policy goal for nearly 10 years[16] and is also recommended by the WHO,[17,18,19] implementation at a wider scale in the UK has so far been fragmented.[20] In 2021, NHS England released guidance to local trusts[21] about delivering full scale UK-wide continuity of carer, with the aim that all women would have a named midwife, providing antenatal, intrapartum and postnatal care under a caseload model. Unfortunately, since then national progress has been patchy, with only 34 teams currently operational (as of May 2024).[22] AIMS supports a staggered implementation of continuity of carer, first being implemented for those most at risk of poorer outcomes, including black and Asian women and those with social disadvantage, as outlined in NHS England's recent Core25Plus5 policy.[23] However, we also continue to campaign for *universal* access to continuity of care for all pregnant women and people and look forward to the day when this is the "standard" model of care in the UK for all, as outlined in our Position Paper on Continuity of Carer. AIMS believes that continuity of carer models are key to a safe, personalised and equitable maternity service, one in which midwives can truly advocate for women and birthing people and get to know and support their individual needs.[20]

AIMS Comment: Please note that this review is referring to midwifery continuity of *care*, rather than continuity of *carer*. Both models include relational continuity, i.e. women or birthing people within these models should be more likely to receive care from the same smaller group of midwives all of whom they have met,[24] compared to those with standard care. For example, Kingston Hospital states that women with their continuity teams "should ideally be cared for by no more than two midwives from their team".[25] However, unfortunately, there aren't as yet widely agreed definitions of either continuity of midwifery care or carer.[26]

[1] Editor's footnote: Please note the difference between 'care' and 'carer'. When care is provided by anyone from even a small team of midwives (6-12 is usual) the mother may not have been able to develop a trusted relationship with any one of them' it is in relational care that the benefits of continuity are thought to lie.

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A Pamphlet of Possibilities

By Bine Browne

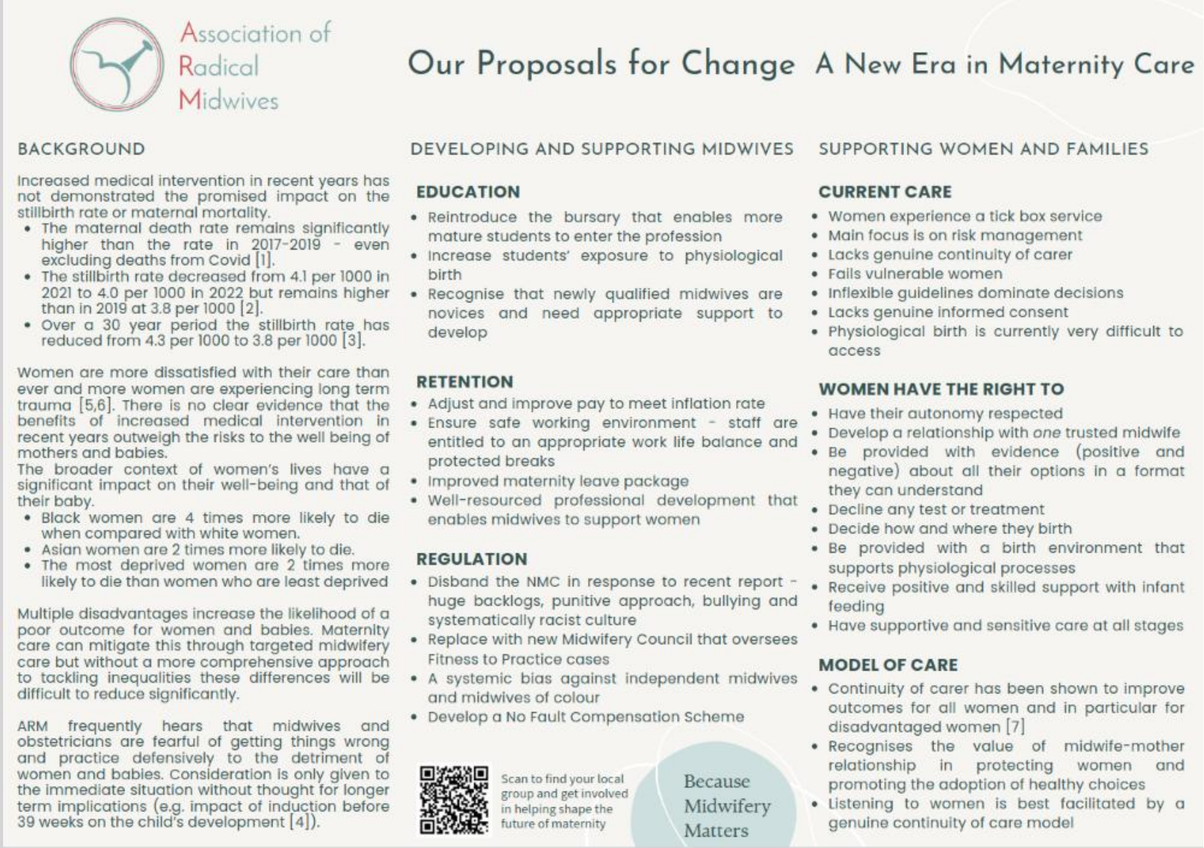
Author Bio: Bine (Abina) Browne has been a midwife since 1984. She has worked in education, management and most recently as a caseload midwife for vulnerable women. She retired in September.

The Association of Radical Midwives (ARM) was formed almost fifty years ago in response to the increasing medicalisation of childbirth, expressed in the induction of labour and the active management of labour. Artificial Rupture of Membranes (also ARM) is a key process of labour induction and the word radical was used in the sense of Radix (Lat. “root”) to express the desire of midwives to return to the fundamentals of care “with woman”. Plus ça change and all that. ARM’s central aim has not changed. We remain committed to the midwife woman relationship being the cornerstone of high-quality maternity care. We believe that inappropriate interventions are damaging to mother and baby. The recommendations of ARM’s ‘New Vision’ of Midwifery Care (2012) were expressed by the ‘Better Births’ document published by the government in 2016.

Over the years ARM has regularly highlighted the failings of the NHS maternity service; the over medicalisation leading to inappropriate interventions, the ineffective ways of working, the focus on organisational needs rather than the woman’s needs, the historic underfunding, the bullying culture affecting both service users and staff. It seemed ironic then, that as various reports[1] into individual maternity services in England were published it was the ‘normal birth ideology’ [2] that the media focused on and demonised. The tragic stories of women’s ill treatment by midwives have been hard to read but not altogether unsurprising (though not excusable) given the fear that plagues the staff (both midwifery and obstetric) of most English labour wards. They are afraid of being under investigation, of being reported to the Nursing & Midwifery Council (NMC) and of losing their PIN (registration number).[3] They practise defensively; their main objective is to survive their shift without incident.

Beyond maternity care, we know that all public services are in crisis,[4] that there is an ever increasing gap between rich and poor and that many people are more unhealthy earlier in life because of their poor housing and low incomes and the stress this causes.[5] The impact of stress on maternal and fetal wellbeing is only just beginning to be properly understood.[6]

Against this backdrop, and recognising the likelihood of change in government, ARM worked on a pamphlet in June and July that finally was given the hopeful title:
Our Proposals for Change: A New Era in Maternity Care
The pamphlet format was chosen as it was thought to be a simple, user-friendly approach to introduce key information, the plan being to send it both electronically and in hard copy to all members of parliament and key stakeholders. We wanted to show that increasing medicalisation isn't the panacea the media portrays; that improving outcomes for women and babies requires a more nuanced and multi-layer approach that recognises the importance of relational care; that those who care must also feel cared for; that physiology matters; that pregnancy and birth cannot be seen in isolation but rather within the wider societal context.



Association of
Radical
Midwives

Our Proposals for Change A New Era in Maternity Care

BACKGROUND

Increased medical intervention in recent years has not demonstrated the promised impact on the stillbirth rate or maternal mortality.

- The maternal death rate remains significantly higher than the rate in 2017-2019 - even excluding deaths from Covid [1].
- The stillbirth rate decreased from 4.1 per 1000 in 2021 to 4.0 per 1000 in 2022 but remains higher than in 2019 at 3.8 per 1000 [2].
- Over a 30 year period the stillbirth rate has reduced from 4.3 per 1000 to 3.8 per 1000 [3].

Women are more dissatisfied with their care than ever and more women are experiencing long term trauma [5,6]. There is no clear evidence that the benefits of increased medical intervention in recent years outweigh the risks to the well being of mothers and babies.
The broader context of women's lives have a significant impact on their well-being and that of their baby.

- Black women are 4 times more likely to die when compared with white women.
- Asian women are 2 times more likely to die.
- The most deprived women are 2 times more likely to die than women who are least deprived

Multiple disadvantages increase the likelihood of a poor outcome for women and babies. Maternity care can mitigate this through targeted midwifery care but without a more comprehensive approach to tackling inequalities these differences will be difficult to reduce significantly.

ARM frequently hears that midwives and obstetricians are fearful of getting things wrong and practice defensively to the detriment of women and babies. Consideration is only given to the immediate situation without thought for longer term implications (e.g. impact of induction before 39 weeks on the child's development [4]).

DEVELOPING AND SUPPORTING MIDWIVES

EDUCATION

- Reintroduce the bursary that enables more mature students to enter the profession
- Increase students' exposure to physiological birth
- Recognise that newly qualified midwives are novices and need appropriate support to develop

RETENTION

- Adjust and improve pay to meet inflation rate
- Ensure safe working environment - staff are entitled to an appropriate work life balance and protected breaks
- Improved maternity leave package
- Well-resourced professional development that enables midwives to support women

REGULATION

- Disband the NMC in response to recent report - huge backlogs, punitive approach, bullying and systematically racist culture
- Replace with new Midwifery Council that oversees Fitness to Practice cases
- A systemic bias against independent midwives and midwives of colour
- Develop a No Fault Compensation Scheme

Scan to find your local group and get involved in helping shape the future of maternity

Because Midwifery Matters

SUPPORTING WOMEN AND FAMILIES

CURRENT CARE

- Women experience a tick box service
- Main focus is on risk management
- Lacks genuine continuity of carer
- Fails vulnerable women
- Inflexible guidelines dominate decisions
- Lacks genuine informed consent
- Physiological birth is currently very difficult to access

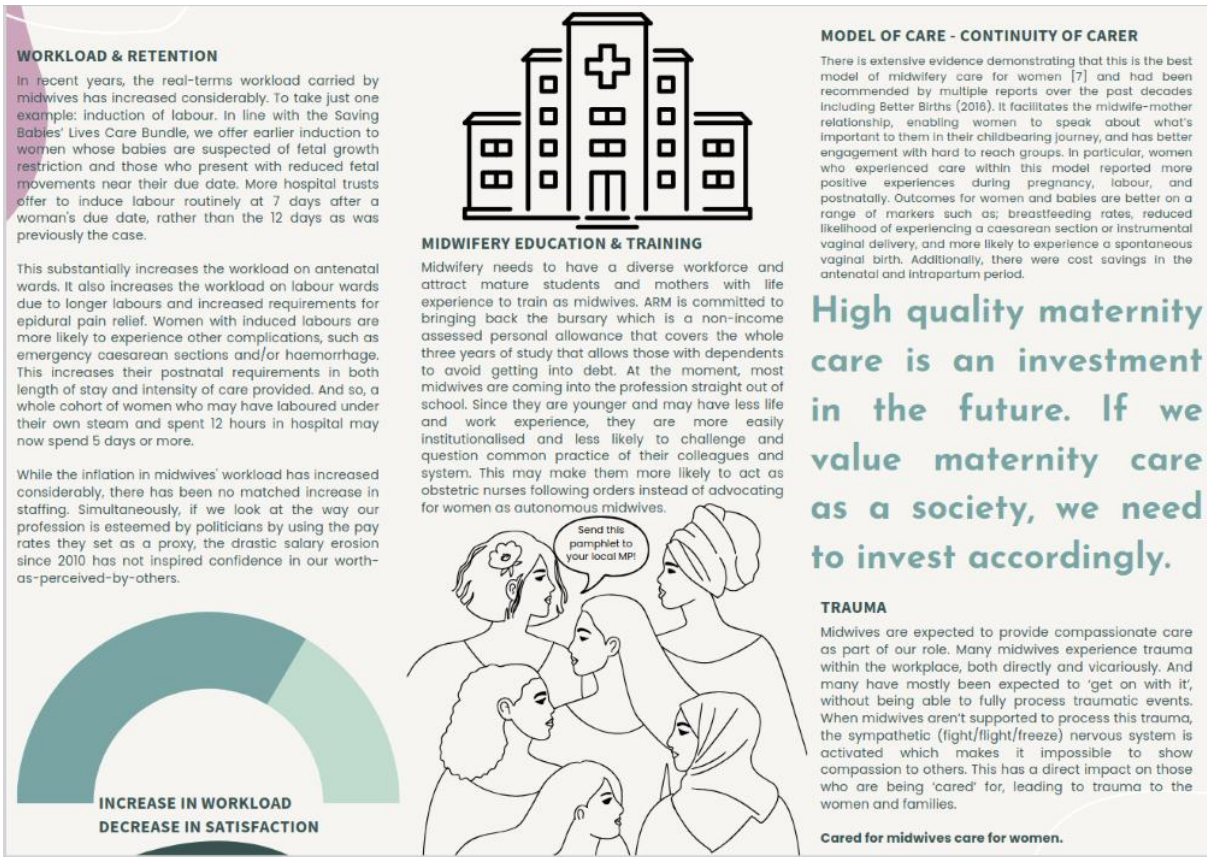
WOMEN HAVE THE RIGHT TO

- Have their autonomy respected
- Develop a relationship with *one* trusted midwife
- Be provided with evidence (positive and negative) about all their options in a format they can understand
- Decline any test or treatment
- Decide how and where they birth
- Be provided with a birth environment that supports physiological processes
- Receive positive and skilled support with infant feeding
- Have supportive and sensitive care at all stages

MODEL OF CARE

- Continuity of carer has been shown to improve outcomes for all women and in particular for disadvantaged women [7]
- Recognises the value of midwife-mother relationship in protecting women and promoting the adoption of healthy choices
- Listening to women is best facilitated by a genuine continuity of care model

The five-member group working on the pamphlet represented NHS midwives from various perspectives: a final year midwifery student, a Professional Midwifery Advocate, a midwife working with women to overcome trauma, a caseload midwife, and independent midwifery represented by the fifth member. We also asked those attending our summer meeting to name the two most urgent issues that should be addressed. Drafts were circulated amongst the ARM steering group for further input. In addition, the AIMS Campaign Team kindly reviewed an initial draft providing helpful recommendations which informed the final iteration.



WORKLOAD & RETENTION

In recent years, the real-terms workload carried by midwives has increased considerably. To take just one example: induction of labour. In line with the Saving Babies' Lives Care Bundle, we offer earlier induction to women whose babies are suspected of fetal growth restriction and those who present with reduced fetal movements near their due date. More hospital trusts offer to induce labour routinely at 7 days after a woman's due date, rather than the 12 days as was previously the case.

This substantially increases the workload on antenatal wards. It also increases the workload on labour wards due to longer labours and increased requirements for epidural pain relief. Women with induced labours are more likely to experience other complications, such as emergency caesarean sections and/or haemorrhage. This increases their postnatal requirements in both length of stay and intensity of care provided. And so, a whole cohort of women who may have laboured under their own steam and spent 12 hours in hospital may now spend 5 days or more.

While the inflation in midwives' workload has increased considerably, there has been no matched increase in staffing. Simultaneously, if we look at the way our profession is esteemed by politicians by using the pay rates they set as a proxy, the drastic salary erosion since 2010 has not inspired confidence in our worth-as-perceived-by-others.

INCREASE IN WORKLOAD
DECREASE IN SATISFACTION

MIDWIFERY EDUCATION & TRAINING

Midwifery needs to have a diverse workforce and attract mature students and mothers with life experience to train as midwives. ARM is committed to bringing back the bursary which is a non-income assessed personal allowance that covers the whole three years of study that allows those with dependents to avoid getting into debt. At the moment, most midwives are coming into the profession straight out of school. Since they are younger and may have less life and work experience, they are more easily institutionalised and less likely to challenge and question common practice of their colleagues and system. This may make them more likely to act as obstetric nurses following orders instead of advocating for women as autonomous midwives.

Send this pamphlet to your local MP!

MODEL OF CARE - CONTINUITY OF CARER

There is extensive evidence demonstrating that this is the best model of midwifery care for women [7] and had been recommended by multiple reports over the past decades including Better Births (2016). It facilitates the midwife-mother relationship, enabling women to speak about what's important to them in their childbearing journey, and has better engagement with hard to reach groups. In particular, women who experienced care within this model reported more positive experiences during pregnancy, labour, and postnatally. Outcomes for women and babies are better on a range of markers such as; breastfeeding rates, reduced likelihood of experiencing a caesarean section or instrumental vaginal delivery, and more likely to experience a spontaneous vaginal birth. Additionally, there were cost savings in the antenatal and intrapartum period.

High quality maternity care is an investment in the future. If we value maternity care as a society, we need to invest accordingly.

TRAUMA

Midwives are expected to provide compassionate care as part of our role. Many midwives experience trauma within the workplace, both directly and vicariously. And many have mostly been expected to 'get on with it', without being able to fully process traumatic events. When midwives aren't supported to process this trauma, the sympathetic (fight/flight/freeze) nervous system is activated which makes it impossible to show compassion to others. This has a direct impact on those who are being 'cared' for, leading to trauma to the women and families.

Cared for midwives care for women.

We struggled with the limitations of the format; trying to avoid overloading it with type but not wanting to miss out key information. ARM believes there is an existential crisis in NHS midwifery and the decision to focus on it exclusively was deliberate. The reality of 21st century midwifery care is disturbing and depressing. It is being strangled by a system that values number counting and clock watching.[7] That said, there are still pockets of excellent practice but these are always under pressure to justify their existence and often stretched to the limit when there are staffing issues.[8] There are also midwives who work tirelessly supporting women to birth well against the odds.

We needed to address the core issues: midwifery care is fragmented, there are few opportunities to develop the midwife woman relationship. Midwives are losing their skills in facilitating physiological birth while some midwives have never been exposed to them.[9] We are approaching a point where almost all NHS midwives will only see birth through a medical/obstetric lens.

Context

The pamphlet opens with an overview of the current situation in maternity care. It deliberately begins with the most recent figures available, showing that increased medical intervention in recent years has not demonstrated the promised impact on the stillbirth or maternal mortality rates. This is significant given the level of increase in both the caesarean and induction rates. The caesarean rate in 2023/24 is likely to be above 40% in England (digital.nhs.uk) and while the induction rate is more difficult to obtain accurately, the official rate was 34% in 2022/23,[10] while our members report rates consistently in excess of 40%. This represents an approximate increase of 14% in the former and a very conservative increase of at least 10% in the latter over the last 10 years.

This shift in the way birth happens has consequences for women and their families. It has consequences too for birth workers. There is little spontaneity. Birth is scheduled, women are processed and the maternity unit runs to an assembly line format. The antenatal and postnatal wards become like holding bays; women waiting to be transferred to the labour ward or go home.

The pamphlet speaks about the impact of increasing levels of induction on midwifery workload and the knock-on impact on workload and retention. Most midwives want to provide sensitive, individualised care, but the systems in place don’t support this. Women are having unnecessary interventions often carried out by midwives who do not believe they should be done. Over time, this is demoralising. Midwives either leave or simply switch off.[11] This in turn leads to insensitive and impersonal care that contributes to women’s poor experience and in some cases trauma.

Midwifery Education

The education of midwives is key to developing a high-quality maternity service. ARM believes it is important that the bursary system is reintroduced to allow for a more diverse workforce and, in particular, mature students and those who have already had children to become midwives. This cohort of students were a regular feature of midwifery courses but since the bursary was abolished, their numbers have fallen dramatically. The bursary is a non-income assessed personal allowance that covers the entire degree programme and allows those with dependents to avoid getting into debt. This system is currently in place in Scotland. All professional groups benefit from greater diversity; midwifery is no exception.

Student midwives' exposure to physiological birth is very limited, many students never see a spontaneous unmedicated birth.[12] This lack of exposure has been seriously impacted by the increasing rate of inductions. More and more women are falling into a category where induction is recommended but without robust evidence to support it.[13] These categorisations say women are too fat, too thin, too old; their babies are too big or too small. As a result the numbers of women birthing in birth centres has also fallen and the opportunities to attend such births are becoming increasingly rare.[14] Developing experiences via simulation might be way forward. However, the experience of physiological birth in the moment cannot be replaced for its impact on students' understanding of birth and their development as midwives.

Retention

Midwives need to have good pay and working conditions. The new government's timely pay increase for nurses and midwives has appeased midwives' concerns about pay for now.[15] However, on-call payments that particularly affect midwives providing caseload care or a home birth service need to be revised upwards to recognise the imposition on one's personal life and, for example, make it possible for midwives who require paid child care cover to work in this way.

The working conditions of midwives are variable. They regularly report they can't take their allotted breaks due to staffing levels or high levels of activity. This is obviously not good practice and midwives who are dehydrated and hungry probably can't be expected to perform to the best of their abilities. Positioning maternity services within secondary health care prevents midwives' time being used effectively. It also means that women's time is not considered. If women are concerned during pregnancy, they are expected to ring a helpline and speak with a midwife who doesn't know them or their circumstances. They may be asked to come to the hospital to be checked. Often, they have to wait hours in a Maternity Triage department. If they were cared for within a caseload model, it is possible their query could be dealt with over the phone by someone who knows their situation or, if needed, be seen closer to home.[16]

Midwives have at least five training days a year to help ensure they remain current in practice developments and skilled in dealing with emergencies. Little or no time is spent in developing midwives' communication skills, in particular how to support women with decisions around birth. Many midwives are afraid of telling women that they can choose not to be induced, that they can take time to decide what they feel is best for them. They fear push back from management or their clinical colleagues, or they lack confidence in initiating such a discussion. Sometimes, sadly, they don't have the time or motivation. We know from women that it is often the way in which they are treated and spoken to that causes the greatest pain and upset.[17] Midwives need to have time away from the clinical sphere to hear women's stories and what women need. Some may need additional support to learn new ways of communicating and caring. There is an 'obsession' amongst NHS Trust Risk teams about interpretation of the fetal heart trace using cardiotocography (CTG) monitoring in labour. The CTG monitor has repeatedly been shown to be a very poor screening tool for fetal wellbeing and yet the number of training hours spent on it are considerable.[18] This time could be better spent on helping midwives to understand what women need from them on their childbearing journey.

Regulation

ARM believes that the Nursing & Midwifery Council (NMC) should be replaced by a new regulatory body led by professional and lay experts, and that the current Fitness to Practise model needs to be completely transformed to one that is compassionate, learning, retentive, and upholds women's choices and autonomy. The NMC is a dysfunctional organisation with a punitive approach to registrants, backlogs of more than five years, and according to Nazim Afzal's Independent Cultural Review,[19] has a culture of systemic bullying and racism. There is a deep-rooted bias against midwives of colour and independent midwives. Many cases have been dragging on for years only for the registrant to be found to have no case to answer when the hearing finally takes place. Midwives are emotionally and financially drained and often decide to come off the register, despite not having done anything wrong other than facilitate women's choice. In some tragic cases they have been known to take their own lives or suffer long-term health problems. It is estimated that at least 27 midwives and nurses have committed suicide following referral to the NMC since 2016.[20]

Supporting Women

ARM wants every woman to have the option of their own named midwife with whom they can develop a trusted relationship to see them through their childbearing journey. The midwife would be part of a small team locally based and with each midwife having a defined caseload of women. We know the continuity of carer model works for women and, in particular, disadvantaged groups. It has been recommended by numerous reports into maternity care and there is a large body of evidence to support its positive impact on maternal and newborn outcomes.[21] It works for midwives too, if it is correctly resourced and supported. Implementing this model of care requires commitment, resources and a vision for the maternity service that values the woman's voice above all others.

ARM believes that midwives need support to support women. We believe that this pamphlet can be used as a guide to best achieve this aim. We encourage all to send and share it with colleagues and MPs to raise awareness and encourage change. AIMS welcomed Wes Streeting in August and presented a powerful argument for the development of continuity of carer model as the standard for all women. We hope we can work collaboratively with AIMS to make this a reality.

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AIMS attends the NHS Confed Expo 2024

By Jo Dagustun

Author Bio: Jo Dagustun has been an AIMS Volunteer since 2017 and lives in Greater Manchester.

In this piece, one of our Campaigns Team volunteers illustrates how attending conferences such as the NHS Confed Expo helps to underpin the quality of our AIMS campaigns work

As an AIMS volunteer, and member of NHS England's Maternity and Neonatal Stakeholder Council, I love stepping beyond the realms of maternity to better understand the context in which we work; this always helps me better understand the potential for improving maternity services, the enablers and the barriers. That's why I registered for the NHS Confed Expo earlier this year. The organisers are the NHS Confederation, "... the membership organisation that brings together, supports and speaks for the whole healthcare system in England, Wales and Northern Ireland ...". The target audience for this conference series is perhaps 'health and care leaders and their teams', but there was quite a mix of delegates and everyone with an interest is welcome.

Very conveniently for me, the conference was taking place in Manchester, and was free to attend, so easy to access and costing just my pro bono time plus train fare (of just £7.80 charged to AIMS). I'm absolutely sure that we got good value for this outlay! Registering was straightforward, and the conference app - available in advance - was really good to use, and helped me understand the shape of the conference, what was happening where and when, and who would be there. Looking at the app, I was reassured that each of the sessions would be dedicated to improving care for patients and the public.

Due to diary commitments, I attended the first day of the conference online. It was brilliant. Not only did online viewers have a premium view of the main stage, we were also treated to backstage interviews with some of the day's key speakers, including Victor Adebowale (chair of NHS Confederation), Richard Meddings (chair of NHS England), William Atkinson (former headteacher and leadership consultant), Amanda Pritchard (CEO of NHS England) and Matthew Taylor (CEO at the NHS Confederation). I was particularly pleased that the livestream included some recorded presentations, taking place elsewhere on the conference floor, including the session I'd really been wanting to attend - In conversation with Tinuke Awe and Clothilde Rebecca Abe, co-founders of 5 x More. It really was my lucky day.

Day two, I attended in person. There were a few sessions that I planned to attend. But first, the exhibition hall. This was a hugely evocative space: the site of the COVID 19 Nightingale Hospital. I started to get my bearings and took a wander around the stands, and soon got into my stride, learning loads as I chatted to exhibitors. These included the Care Quality Commission, The Healthcare Improvement Studies Institute (THIS Institute), the Alliance Manchester Business School, AstraZeneca UK, the Healthcare Financial Management Association, the Institute for Healthcare Improvement, Managers in Partnership, Net Zero NHS, NHS Blood and Transport, NHS England, NHS Property Services, and the Nursing and Midwifery Council (the NMC).

There was one person that I had really wanted to meet that day - Sonah Paton, a fellow member of Stakeholder Council and co-founder and managing director of Bristol-based Black Mothers Matter. It was so good to have an unhurried first chat with Sonah after she'd completed her session.

At another stand (belonging to CAHN - the Manchester-based Caribbean and African Health Network), I was explaining that I really appreciated the work of this charity, and that I really ought to connect with their Chair, but that I was a bit nervous of doing so. You can maybe guess who then walked up, the Chair herself, Faye Ruddock ... I took a breath and a wonderful conversation followed (mainly focused on our shared interest in the CORE 20+5 initiative and the Enhanced Midwifery Continuity of Carer model of care). This underlined to me the benefits of attending such events in person, and finding the courage to speak up.

I learnt about so many new organisations and issues that day - all important to a well-functioning maternity service. I gained insight into the panel of lawyers engaged by NHS Resolution, and started to imagine a bespoke maternity training programme for them ;-)

At only a few stands was I met with people who clearly had a script to follow, presumably without the autonomy to divert from that and talk to what visitors to the stand were interested in; I moved on quickly.

And then, and it was now three o'clock and I hadn't yet made a session, I made my way to the main stage. En route, however, I saw a huddle of maternity people I recognised in a side room, and joined that session instead. And what a great session it was: Working with women and families to improve equity in maternity and neonatal care. Quite unplanned, I even found myself asking a question (about CORE 20+5 and continuity of carer) at the end of the session. I got a really positive response that led to some very good brief chats with some of the speakers and others attending the session, all the way to the exit at the end of the day, as well as a follow up email (to which I haven’t yet had a proper response, but I’ll keep chasing!)

I couldn't have planned a better day, and that's without mentioning the short exchange with the Chair of the NHS Confederation, Victor Adebowale, and a question posed to the Chair of NHS England, Richard Meddings via the app. (Not that I ever got a response to the latter, mind you ...)

The key themes I returned to throughout the Expo were: good governance, transparency and equity, with a particular focus on progress with the maternity element of the CORE20+5 initiative (and in particular where we are with the implementation of enhanced midwifery continuity of care teams). It was a real treat to find others with similar interests, to listen, to share information, and to have honest conversations. For a small charity such as AIMS, our campaigns work will only be effective if we develop strong collaborations.

This was the first time I'd attended this annual event. I come away with the sense that it was a great opportunity for AIMS to listen, to learn, and to collaborate. I will certainly look it up next time it's in town, and maybe I’ll spot you there! Save the date: Manchester Central, June 11-12 2025.

AIMS urges action as newly released analysis demonstrates better care when ‘full pathway continuity of carer’ is in place

By the AIMS Campaigns Team

Published
NOVEMBER 2024

NHS
England

Analysis of selected questions from the CQC Maternity Survey 2023

Continuity of Carer analysis

March 2024

Released November 2024, via the NHS Futures Hub

With new real-world evidence showing the positive difference it makes, AIMS calls for a full pathway ‘continuity of carer’ model of care to be a key plank of the new Government’s renewed maternity transformation policy. We urge the new Government to recommit to a rollout strategy that prioritises those at most risk of poorer outcomes. Integrated Care Systems (ICSs) and local NHS trusts should also take note of the insight provided by this analysis, and ask not whether they should implement this new model of care but when.

On a range of measures related to key issues, this just published analysis of the Care Quality Commision (CQC) Maternity Survey 2023[1] demonstrates that ‘full pathway continuity of carer’[2] is associated with improvements across multiple aspects of high quality maternity care. These issues include: confidence and trust, help and advice, the opportunity to ask questions, being given sufficient and relevant information, and healthcare professionals being aware of women’s previous history (so they don’t need to tell their story over and over again). With the maternity services under the spotlight for widespread failings across England, ‘full pathway continuity of carer’ is a model of care that the NHS urgently needs to get in place, for all women and families.

With current staff shortages, progress to deliver on the Better Births (2016) recommendation varies greatly across England. AIMS urges that implementation should proceed at pace, as the new Government recommits to this vital policy goal, ensuring that resource shortages are addressed and drawing on what we now know about implementation challenges.

As many women and families around the country will attest, and as Better Births predicted based on its widespread consultation, implementation progress to date has been widely welcomed by maternity service users. This partial implementation has allowed real-world data to be collected by the CQC on what difference this model of care seems to make. **Earlier this month, additional analysis was released that offers ever greater insight, bridging the gap between what we hear women say - information that is too often brushed aside as poor quality (anecdotal) evidence - and what is now on the official record as statistically significant evidence from a robust survey.**

The main CQC 2023 maternity survey data was published in January 2024. The latest analysis, published by NHS England in November 2024, looks beneath the headlines exploring women's survey responses about different aspects of their care in relation to the model of care they had received. Importantly, it also considers this through an equity lens[3] in line with the CORE20PLUS5 national approach, which has called for a deliberate rollout strategy that targets action on women we know are likely to have the poorest maternity outcomes.

Key findings from newly published analysis

- A **targeting strategy** can be observed
    - Women living in the most deprived areas of England were most likely to report receiving full pathway continuity of carer (antenatal, intrapartum and postnatal).
    - Women from Arab and other groups, as well as Asian/British Asian women, were most likely to report receiving full pathway continuity of carer. White women were least likely to report receiving this model of care.
    - Effective targeting was not always in place for Black women and families. For example, Black and Black British women seem to have had least access to any form of continuity through to the postnatal period.

- There are significantly better reports of care for women reporting **full pathway continuity of carer**
    - Of 50 of the 51 measures analysed, women who experienced full pathway continuity of carer reported a better experience than those who received antenatal and postnatal continuity. They also reported a better experience than those who received no continuity at all.

- We can now see a significant **difference between women's maternity experiences, according to whether they have received full pathway**

continuity of carer or fragmented care. Here are some example comparisons between the experiences of those who report receiving full pathway continuity of carer and those who report receiving none. Together, they speak powerfully to the issues of **listening to women, informed consent and high quality responsive and personalised care:**

- Was out of hours **support for baby feeding available?** 73% v 30% said ‘yes, always’
- After the birth, **did you have an opportunity to ask questions about your labour and birth**? 73% v 37% said ‘yes, completely’.
- Did caregivers do everything they could to help manage **pain during labour and birth?** 82% v 54% said ‘yes, definitely’
- **Were your concerns during labour and birth taken seriously**? 91% v 74% said ‘yes’
- If you were induced, did you get **appropriate information and advice around the risks and benefits of induced labours?** About the benefits, 92% v 73% said ‘yes’. About the risks, 87% v 58% said ‘yes’.
- Were you given appropriate **advice and support at the start of labour**? 94% v 78% said ‘yes, definitely’
- When making contact with midwives and doctors during pregnancy, did you get the **help and care you needed**? 88% v 59% said ‘yes, always’
- During pregnancy, did you feel that **you were listened to**? 92% v 62% said ‘yes, always’

We are fortunate to have the independent annual CQC Maternity Survey of women’s experiences with the maternity services in England. These survey results form a key part of all maternity feedback collected, and contribute to an understanding of where the maternity services need to be improved. AIMS would like to thank the CQC for their work on this survey, and staff at NHS England for making this latest data analysis available.

With such real-world evidence showing the positive difference that it makes, AIMS calls for the full pathway ‘continuity of carer’ model of care to be a key plank of the new Government’s renewed maternity transformation policy, and asks the new Government, ICSs and local NHS hospital trusts to recommit to a rollout strategy that prioritises those at most risk of poorer outcomes. This new analysis makes it clear to AIMS that we cannot deliver safe, personalised and equitable care without it.

[1] Editor's note: The full NHS England data set (dated March 2024, and released in November 2024) is available in the Maternity and Neonatal Hub area of the NHS Futures website: FutureNHS Home - FutureNHS Collaboration Platform. Or click here for the downloaded document on the AIMS website.

[2] Editor's note: **What is 'full pathway Continuity of Carer'?** In 2016, Better Births recommended a model of midwifery care called 'continuity of carer'. This is a relational model of care, where small teams of midwives and doctors - supported by the wider multidisciplinary team - work together so that each woman is supported by an individual midwife throughout her maternity journey, from antenatal care, during labour and birth, through to postnatal care. This is what we mean by full pathway, the pathway from first to final contact with the maternity services. To ensure maternity service provision that is safe, personalised and equitable, AIMS believes that a robust and sustainable model of relational care (or continuity of carer) should underpin all maternity service provision, for all service users, across the UK. AIMS looks forward to a time when continuity of carer will be the standard model of maternity care for all. We ask: What other approach will work to achieve the aspiration to become a maternity service that is truly able to 'listen to women'? For more information, please read the AIMS position paper.

[3] Editor's note: An equity lens is a planned strategy within an organisation for looking at (the lens part) its values, policies, actions and impact, with the focus on equity and inclusion. The aim is to ensure that everyone can benefit equally from the work of the organisation even when their needs are different and need to be met in different ways.

What has the AIMS Campaigns Team been up to this quarter?

By the AIMS Campaigns Team

Written outputs:

- Social media campaign on Continuity of Carer I statements.
- AIMS submitted comments on the NICE Draft guideline on Maternal and child nutrition
- Responded to Patient Safety Commissioner survey on Principles of Better Patient Safety

Conferences and meetings attended:

- 5th August: Continuity of Carer Huddle
- 6th August: Monthly Campaigns Team meeting
- 2nd September: Continuity of Carer Huddle
- 3rd September: Team leads meeting
- 10th September: Monthly Campaigns Team meeting
- 10th September: Nuffield Trust Study on Nursing & Midwifery Training Standards
- 12th September: Implementing Midwifery Continuity of Carer
- 12th September: RCM Research Prioritisation project steering group
- 16th September: Care Opinion Northern Ireland online meeting
- 17th September: Wales & South West Maternity & Midwifery Festival online
- 19th September: NMPA (National Maternity and Perinatal Audit) Clinical Reference Group
- 23rd September: Black Maternal Mental Health Week webinar: Understanding the Disparities
- 30th September: Crochet project Threads of Protest meeting
- 30th September: Campaigns Team Social Media Group work
- 3rd October: Continuity Network meeting
- 3rd October: MNISA (Maternity & Neonatal Independent Senior Advocate) Evaluation - Independent Advisory Group meeting
- 7th October: Continuity of Carer Huddle
- 8th October: Monthly Campaigns Team meeting
- 8th October: RCM Sustainability in maternity' webinar
- 9th October: Rehumanising maternity care following the [NSW Australia] Birth Trauma Inquiry webinar
- 10th October: Virtual conference presenting the 'Saving Lives, Improving Mothers' Care' report 2024
- 14th October: ENCA Meeting online
- 16th October: WHO webinar about their work on transitioning to midwifery models of care

- 16th October: Maternity & Midwifery Hour: Experiences of pregnant women living with obesity: access to antenatal care
- 17th October: RCM Research Prioritisation project steering group
- 18th October: Webinar - Maternity JRCALC Guidance Update 2024
- 18th October: NHS-E maternity and neonatal stakeholder briefing re Change NHS
- 21st October: International Roundtable meeting re joint action with relation to obstetric violence
- 24th October: Maternity services failings: can we try a different approach?
- 30th October: 1-1 with Stakeholder Council colleague, Tracey Bignall at the Race Equality Foundation

Who we have been corresponding with:

- 14th August: Open letter to Wes Streeting, Secretary of State for Health & Social Care

What we have been reading:

- NICE Interventional Procedures Guidance: Balloon disimpaction of fetal head at emergency caesarean delivery
- Supreme Court ruling on McCulloch and others (Appellants) v Forth Valley Health Board (Respondent) (Scotland)
- The POOL cohort study Maternal and neonatal outcomes among spontaneous vaginal births occurring in or out of water following intrapartum water immersion: The POOL cohort study
- Report on maternity services in Northern Ireland: Professor Mary Renfrew's report: Enabling Safe Quality Midwifery Services and Care in Northern Ireland.
- Change NHS: Government issues rallying cry to the nation to help fix NHS
- Review of patient safety across the health and care landscape: terms of reference - GOV.UK
- Maternal Mental Health Services Progress Report October 2024

Thanks to all the AIMS Campaigns Volunteers who have made this work possible. We are very keen to expand our campaign team's work, so please do get in touch with campaigns@aims.org.uk if you'd like to help!