AIMS For a better birth...

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

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By Alex Smith

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]

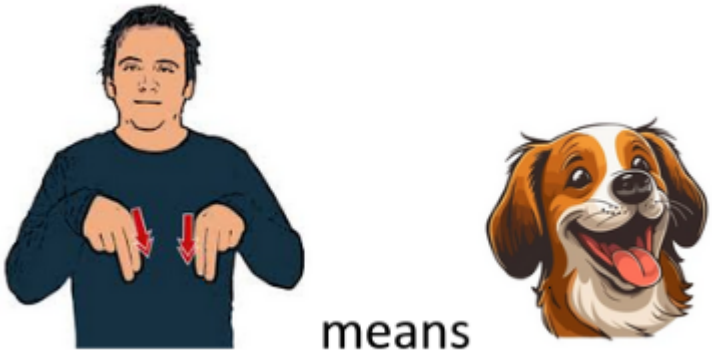
The history of BSL is marked by oppression from hearing people.[6] Oppression and marginalisation is ongoing. For example, almost all teachers of the deaf, and most BSL teachers, are hearing. This is because deaf children have not been given full access to education and consequently have not been supported 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.

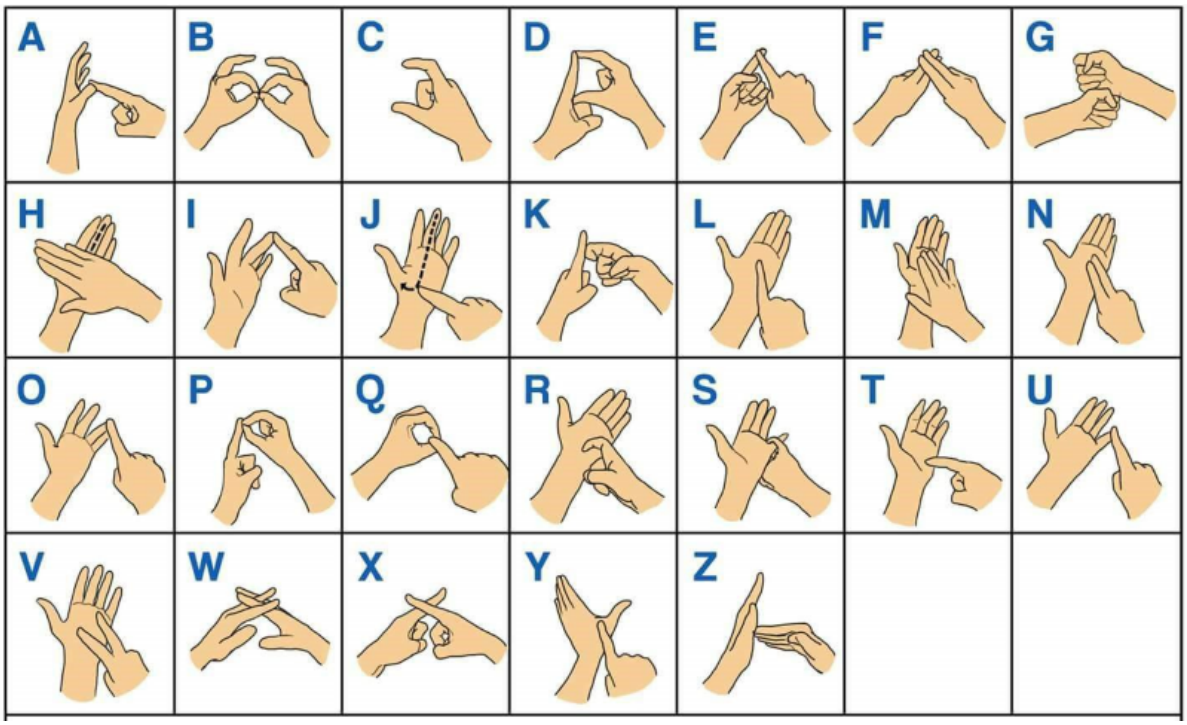
In the meantime, what can you do as a maternity services improvement campaigner and/or health practitioner?

- 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 thisvideo. 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 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.
- Include Deaf
- Include Deaf is a platform that helps organisations identify and fix where Deaf customers and employees are being unintentionally excluded
- .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 fundinghearing 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.

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.

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