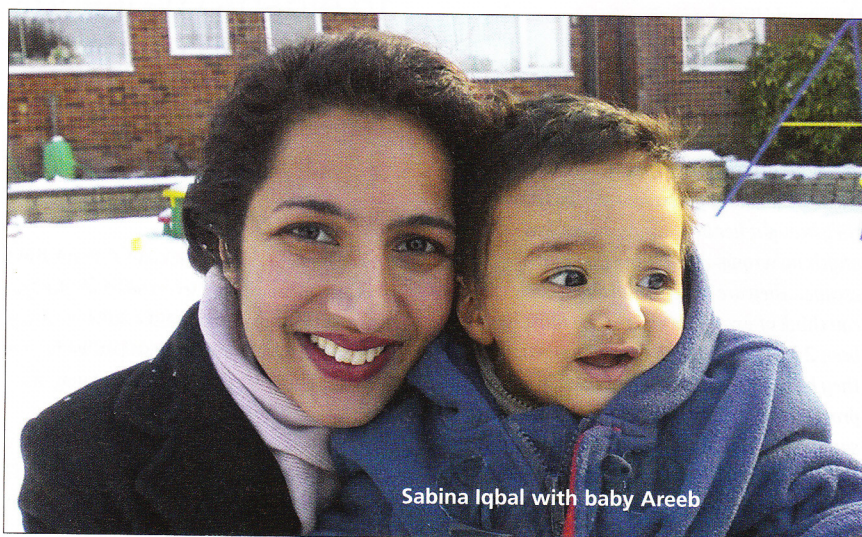


Championing the needs of deaf parents



Francesca Robinson celebrates the work of a charity and its founder, Sabina Iqbal, in improving the maternity experience of an often-sidelined group



Sabina Iqbal with baby Areeb

Deaf parents often complain that midwives and other healthcare professionals lack a general awareness or understanding of their needs during pregnancy, birth and the postnatal period.

According to the charity Deaf Parenting UK there are an estimated nine million deaf and hard of hearing people in the UK and many are parents. But despite the 1995 Disability Discrimination Act many deaf women, when pregnant, encounter difficulties in accessing the information they need from maternity services.

The universal language of deaf parents is sign language but deaf parents find it may not be always available despite the fact that organisations are legally obliged to provide this service for them.

Common problems aired by deaf parents, who contact the charity's helpline, include attitudinal barriers among midwives or health visitors who are unable to communicate in sign language or who are not deaf aware and obstacles in accessing mainstream parenting classes and information on birth options.

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risk of suffering from postnatal depression because they are more likely to experience mental health problems as a result of isolation due to communication barriers.

Another concern is that the children of deaf parents are more likely to suffer from a delay in development of their language skills during the early years and may fall behind their peers when they start school.

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The problems deaf parents-to-be can face were highlighted in 2004 by a BBC documentary about a couple expecting their first baby. Communication during birth and in consultations afterwards with the GP took place by pen and paper.

In another case highlighted by Deaf Parenting UK a deaf woman had two babies, both by caesarean but was never given any information about different birth options. When she had her third baby with a different partner full information was provided and she was only then able to choose a different birth option.

Birth of a charity

Deaf Parenting UK was launched in 2001, initially as a project by Sabina Iqbal following research she conducted on gaps in services for deaf parents within the UK. The project grew and flowered and became an independent charity in 2004, designed to empower and support deaf parents and to campaign for their rights and raise awareness of their needs. During the last year the organisation has been put firmly on the map by Sabina's tireless campaigning which has won her no fewer than seven awards. The accolades include an award from world business leaders for innovative use of knowledge and information management in the charity sector, a runner-up prize in the equality and diversity ►

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category of the Guardian's Public Services Award and most recently a "highly commended" in the 'Community Builder' category of the Beacon Fellowship Charitable Trust Awards. Sabina also won the Women of the Future Voluntary Award in 2008 for women breaking the high glass ceiling. Most recently, the Muslim Women Power List has named her as one of the most influential Muslim women in Britain today.

Sabina, herself a deaf parent, says to date deaf parents have been voiceless members of society: "Many deaf parents miss out so much because we are deaf and we can't

hear conversations among parents and professionals. Much of the information and many of the services are not accessible to meet our needs, even though deaf parents are 90 per cent likely to have hearing children. So how can we make informed choices and decisions about our children's lives – including their education – if we can't access the basic information that many take for granted?"

Positive experience

A lack of awareness of the needs of deaf people is, she says, widespread among healthcare professionals: "Deaf parents

should be accepted for who they are, not excluded because they are deaf," she says.

But Sabina also has praise for midwives and says deaf people can also have positive experiences of pregnancy and childbirth. She cites as an example of good practice the birth of her own children: Samaira, now two, and Areeb, one. "Because my husband Asif is also deaf I felt it was vital to have a BSL [British Sign Language] interpreter at the birth to enable him to communicate with the staff in case anything happened to me. He was a brilliant support at my birth – I had a water birth for both children and it was a quick 3.5 hours for Samaira and 3

Some experiences of deaf women during pregnancy and childbirth

"Because my first language is BSL, I really wish all information about pregnancy and birth was available in BSL, but nothing is available. It was difficult to access information from any bookshop or library in general parenting books because of the high level of English and I had to rely on my husband or someone to explain the information from English into BSL."

"When I found out I was pregnant I was so shocked as it was unplanned. A few days later, I went to see a doctor. An interpreter was present and the doctor referred me to a midwife. I told the midwife I needed to have an interpreter throughout my pregnancy and I wanted to choose the interpreter who is also my friend. Later on in the pregnancy my GP was trying to make me choose other ways to have someone who can relay for me, for example, asking if my partner is hearing (actually Colin is deaf), or a hearing friend or my mum, because the interpreting fees are high and they wanted to save money."

"I had a tour of the maternity ward. I had to phone a couple of times beforehand to make sure that the hospital got me an interpreter. I went, and it turned out that they had booked a communication support worker, who had only Level 2 (a qualification in BSL which does not include any interpreting skills). Worse still, it was someone who didn't have any experience with childbirth, so he didn't have a clue what all the terms were about."

"During the first night after my baby was born, I was asleep and I couldn't hear my baby crying. The baby alarm that vibrates wouldn't work as the ward had many crying babies and the alarm kept going off. So I told the nurse to alert me if my baby cried while I was sleeping, but she didn't. Instead, she woke me and had a go at me, saying, "your daughter has been crying". I told her that I couldn't hear my daughter crying so how could I know if she had been crying?"

"The midwife came for a check up of the baby and me. I made sure that my hearing mother wasn't around then, because then the midwife would only talk to her, and not to me."

"I put in big capitals on my birth plan that I was hard of hearing and how they could help me. I think that helped a bit, but when the crunch came, nobody told me what was going on. I was cut when I didn't want to be and I did feel ignored. When the baby was born, they told my husband it was a baby girl – and I was lying on the bed, exhausted and forever asking whether I had a baby boy or a girl while the midwife and the nurse were cleaning my baby. The midwife was stern and told me that I had a girl. That midwife came on shift while I was in labour so she wasn't aware that I am hard of hearing."

"I had poor access to communication support during antenatal classes. I had a 'communicator' but she was BSL Level 1 (a basic qualification in BSL which does not include any interpreting skills). The hospital booked her. I missed out on lots of information. I saw a video about preparing for labour but it had no subtitles and no BSL translation on the video. The communicator wasn't much help, as I didn't understand the video. I would have preferred to go to antenatal classes specifically for deaf parents so that I was in a signing environment. Maybe I would have understood more from those classes and shared more enthusiasm with other deaf parents. Instead, I had classes where I was the only deaf parent and I was so isolated, I couldn't interact with other parents so I became quiet and felt left out from the chit-chats between them."

Source: Iqbal (2004)

hours for Areeb.

"The birthing centre where I had my two babies was very supportive and deaf aware, mostly because I made an extra effort to meet them prior to the labour to make them aware of my needs. All the information was available in my hospital maternity notes.

"The midwife had not met deaf parents before but she warmed to me at the first appointment. I explained about my needs and expectations and even gave her a copy of my book, *Pregnancy and Birth: a Guide for Deaf Women* (Iqbal 2004). When I had my second child my midwife and health visitor were fully aware of my needs and looked at me face-to-face so that I could lip-read. If further discussion was needed then an interpreter would be booked to meet our communication needs."

Sabina explains how she was able to look after her new babies: "Being deaf, we were unable to hear the baby crying or any other baby sounds but because we could see we were able to tune in with our baby's

emotions visually seeing if they were upset, happy, sad or tired. It just took time and practice to get used to each baby. We currently have a silent alert pager, which alerts us when the baby cries. We have two pagers, one for each child, so we know which one is crying."

Supportive website

Through its website, Deaf Parenting UK offers information, advice and support to deaf parents and the healthcare professionals working with them. The charity provides deaf parenting skills courses in sign language, run by deaf trainers and covering all aspects of parenting.

It also offers consultancy services to NHS trusts such as deaf awareness training and reviews of the accessibility of maternity services to ensure they are compliant with disability and equality legislation.

The charity also offers resources for midwives. Sabina's book includes a section for health professionals with useful deaf

awareness tips. In addition, midwives can access a newsletter which will keep them informed of issues concerning deaf parents.

Maria Miller, Shadow Minister for the Family and a supporter of the charity, urges midwives to find out more about the needs of deaf parents: "All families need to know that the support is going to be there when they need it particularly at those pressure points that families face. More has to be done to ensure that communication is not a barrier whether it is during pregnancy, or around the time of the child's birth or indeed through parenting classes." **TPM**

Francesca Robinson is a medical journalist

Reference

Iqbal S (2004). *Pregnancy and Birth: A Guide for Deaf Women* www.forestbooks.com/pages/Categories/Books/1904296033.html

Further information

Deaf Parenting UK website: www.deafparent.org.uk

Homeopathic Remedies and Creams for Pregnancy, Childbirth and the newborn



The Helios Homeopathic Childbirth kit contains 18 safe and gentle homeopathic remedies specifically for use during pregnancy, labour and postnatal symptoms. Each kit is accompanied by an information booklet giving an introduction to homeopathy, an A-Z of complaints that can be treated and a materia medica section detailing the main uses of each remedy. Our natural plant based creams are formulated to ease varicose veins, piles and stretch marks and soothe nappy rash, cradle cap and other minor skin complaints and first aid situations.

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GBS is the UK's most common cause of life-threatening infection in newborn babies

- 1/1000 babies aged up to 3 months develops GBS infection – usually septicaemia, pneumonia and/or meningitis.
- Most babies recover from their GBS infection, but around 10% of these sick babies die and others suffer long term problems.
- Offering intravenous antibiotics in labour to women in recognised higher-risk situations would prevent most GBS infection in babies.
- Informing expectant parents about GBS and alerting them to the signs of GBS infection in their baby is key.

GBSS, a charity with a respected team of medical advisers, provides information on GBS for parents, expectant parents and health professionals.

The standard tests for detecting GBS carriage in pregnant women give many false negatives. Two private laboratories offer sensitive testing by post in the UK (contact Mullhaven on 01234 831115 and The Doctors Laboratory on 020 7307 7373 for free test packs – payment is made when the samples are sent for testing).

All our leaflets/posters are available FREE from our website, hard copies directly from us



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Group B Strep Support preventing GBS infection in newborn babies

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