AIMS For a better birth...

When Health Care Providers can't see what their role should be

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Becoming a parent for the first time is a life changing and sometimes daunting time for any new mum or dad.

For some parents, there are additional challenges. This is a true story, shared with permission.

Imagine you are a couple who are expecting their first child. This couple attend all their appointments with their hospital based consultant and midwife together. At the twenty week scan they discover that they are having a little boy. They are overjoyed!

One morning, shortly after this scan, there is a knock at the front door. Mum goes to answer it, and opens the door to a lady from the Social Services Safe Guarding Team.

Wondering if you missed something? Well, this couple are both visually impaired. But is this their additional challenge? Think about that for a moment. They have managed to get themselves to their appointments independently. They live independently with no outside help. They are used to their lifelong eye conditions and have learned to do things for themselves in spite of their visual impairments. So, why did the maternity staff call in the safeguarding team? Sadly, it's a theme that we are seeing more and more of. This particular couple had shown an interest in their midwife finding out what help might be available for them to go out as a family when their son was born. However, this was not what they

received. Safeguarding services are not support services. This became their additional challenge, not their visual impairment.

After the social worker has gone, Mum sits down and confesses to Dad that she does not want to give birth to her baby because now she is frightened they will take him away. Many meetings follow with Social Services and midwives. They are all assessing how well the couple will cope when the new baby comes. Mum feels increasingly on edge and worried.

Mum develops high blood pressure, a condition not helped by the stress she's under, and before her due date comes she is in hospital being induced. It is a long and exhausting labour and when baby is finally born, he is placed on Mum's chest and latched on to feed. Take note of those two words: "latched on". Mum was not shown how to latch her baby, it was done for her. Next time baby is hungry Mum asks for someone to show her how to latch him on. "Oh, we'll latch him on for you," was the response. Mum replies that "I'd rather be shown so I can do it myself when we go home" but no one was sure how to help her because she couldn't see.

They advise that she hand expresses into a cup and syringe feeds it to baby. Hand expressing is not always easy at the best of times, without the two added complications of not being able to see well enough to catch the milk, and not being able to tell if the syringe has drawn up any air. So Mum has to give formula.

More often than not, I and my fellow peer supporters at Blind Mums Connect,[1] hear many women's stories of being told "you won't be able to latch the baby on because you can't see where your nipple is. It's probably best if you bottle feed." This is staggering! Before we resume our story of this couple, consider for a minute the steps that we take when making a bottle.

Step one, measure, for example, 2oz of boiling water into a bottle. Now imagine doing that with no sight, or very little sight. Even if visually impaired Mums are independent in the kitchen, making meals for the family, making their own cups of tea etc and the kettle does not frighten them, markings on bottles are not easy to read, even for Mums with partial sight. So how do you get round step one? Purchase a very expensive set of talking kitchen scales. Stand the bottle on the scales and set to zero. Pour in the hot water, without leaning on the bottle and adding extra weight to the scales, and very, very slowly so you don't go over the number of ounces required.

Step two, measure the formula. Measure a level scoop of formula without packing it down as you level it off. Pour it into your bottle. Made a mess? that's very normal. Now all you have to do is shake it and cool it. Simple wasn't it? No! And some visually impaired parents decide it's too hard, resulting in them buying machines such as the Perfect Prep, with all its added health risks, or asking partners to measure the water before they leave for work and stick it in the fridge, so all they have to do is warm the water up in the microwave and add the formula. Or maybe they'll ask them to make all the bottles and shove them in the fridge to be warmed as required. Don't misunderstand me, a lot of visually impaired parents make up bottles safely using the method of talking scales, and make them up as required, but for some it's just too

much. Considering Mums produce milk at the right temperature and tailor-made for their own babies, making formula, with all its potential risks and variables, suddenly seems like more hassle than anything else, especially with the added complication of sterilising and making sure all bottles are clean of formula in the first place.

So let's get back to our couple. They have been in hospital a week now. They are both longing to be back in their own familiar surroundings where they can care for their baby independently but the hospital are reluctant to discharge them. Mum struggles to bond with baby because she is unsure how long she will be allowed to keep him. Dad steps in and does nearly all the work with baby.

The couple finally leave for home after their health visitor becomes involved and speaks to the hospital on their behalf. When they are home as a family, breastfeeding support is called in, but Mum's heart is no longer in it. She instead expresses for her son and gives it to him in place of some of his formula bottles. Her reason is that if she was breast feeding, the baby would be hungry if he was taken away. Social services visit again. At the end of the meeting the health visitor asks if she can come and visit again. When she was asked by the couple if she needed to come back, her response was "no". The couple told her that they did not want any more visits because the unnecessary stress and anxiety had spoiled the joy of the pregnancy and they didn't want the impending visits hanging over them to spoil their time with their new baby. There are so many eyes on this couple and none, apart from their health visitor, offered the support that they had asked for in the first place. The whole experience leaves the family shattered.

Sadly, there are so many cases of this now, and extra involvement is not always easy to shake off, with some parents being asked to look after dolls to prove they can look after a baby. How many sighted mums have to do this?

I am pleased to report that over a year later, Mum and baby have a strong bond and the family has healed. But their story is one that is now becoming more and more common.

There is no reason to assume that when you encounter a visually impaired mother or father that intervention is needed. Rather, taking a little time to get to know the couple would help you understand their basic needs throughout the time that you're supporting them. Of course, there are going to be exceptions to this, and at times extra support or intervention is necessary. But seeing a visually impaired parent shouldn't automatically cause the panic button to be pressed.

Here are a few examples of ways that healthcare providers can put visually impaired parents at ease:

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Say who you are when you walk into the room. This is vital, especially in hospitals or in birth settings. Just a cheery "Hi, it's just Anne again, come to see how you're doing," or if you haven't met someone before, "Hi, I'm Anne, I'm the midwife who will be looking after you today." It might sound very basic, but being in an unfamiliar environment is disorientating at the best of times when you are visually impaired, let alone being in pain as well.

- Please say if you have brought anyone into the room with you. For example, "This is Doctor Smith, she's just come with me to talk about how things are going."
- Don't be afraid to ask how much the parent can see. If you don't ask, you won't know what support they might need, for example being shown round the room they're in to orientate themselves, or being assisted to find the toilets. People refer to their visual impairment in different ways. For example I'd say, "I'm totally blind, I can't see anything at all," whereas someone else with sight loss might say "I'm partially sighted, I can see things up very close." If you're unsure what term to use yourself, the term "visually impaired" covers all bases.
- If there is a fully sighted person with the visually impaired woman, please don't talk only to that person rather than the visually impaired person. Equally on the rise are stories of visually impaired Mums being given little support because they assume that their sighted person accompanying them to their appointment, be that their partner, mother, or next door neighbour giving them a lift, will be doing everything when she and baby go home. This cannot, and should not, be assumed. I have a wonderful, supportive family. My Mum or one of my sisters have accompanied me to all my hospital visits during my pregnancies. My Mum has stayed in hospital with me for days at a time as my birth partner. I have had support when I get home in the early days. However, I care for my child myself. Every time someone addresses a question to my Mum like, "How many wet nappies does baby produce in a day?" I want to shout, "Hello! I'm the baby's Mum!" Or someone will make a suggestion and then say, "Well you've got your mum to help you." While this is true, it doesn't take away from the fact I'm the parent. I'm the one who takes care of my baby day to day. Of course, there will be some families who will try and take over, and in such cases visually impaired parents need support to build up their confidence to do things themselves. Organisations such as Blind Mums Connect[1] can help in various ways such as providing feeding support, assistance with slings and getting out and about.

Please don't assume that helping a Visually Impaired mum to breastfeed will be any more difficult than helping a sighted mum to breast feed. The mechanics are all the same. It might take some extra time, or a little bit of thinking outside the box if it's not working, but it is totally possible. Keep in mind that the cross cradle position is not the easiest for a visually impaired woman as it means she does not have any hands to feel when the nipple is opposite the baby's nose, and it can be quite frustrating and feel very

awkward. Blind Mums Connect have peer supporters who can offer specific help with positioning.[1]

I have had very good experiences with midwives in hospital and with some of my community midwives. However, before my daughter's tongue tie was discovered, and it was decided she was not putting on enough weight, a nursery nurse came out to see me with my health visitor. She spoke to me as if I should be so grateful that she had made me her last call of the day to come and explain laid back breastfeeding to me. I was quizzed about the content of my daughter's nappy. "Does it have seeds in it?" when I explained that I didn't know, she said "Where's your Mum?" to which I replied, "I am 25 years old! I do not live with my Mum! She is not here 24/7!" She then asked, "Did you bath the baby yourself?" When I snapped back, "Yes, I did", she said in a very patronising tone, "That's amazing! and you dressed her too!" Needless to say, I did not take to her. Quite often, you see, the tone of voice carries a lot of weight for someone who relies on their ears rather than their eyes.

Health Care Providers dealing with vulnerable new parents have the ability to make a woman feel supported… or suspected. There is a big difference. Just by not making assumptions, providers could change the story for visually impaired parents, and allow them to enjoy their children with the same rights as fully sighted Mums and Dads.

Philippa Lomas is a peer supporter with Blind Mums Connect, and a mother's supporter with ABM. She is also the mother of two girls, and is visually impaired.

References:

1. Blind Mums Connect Website: www.blindmumsconnect.org.uk Blind Mums Connect Helpline: 01905 886252