Scott's story

Getting pregnant

In 2014, Scott's partner became pregnant. They had reached a mutual decision to have a baby and started trying. They were surprised at how quickly she became pregnant. They took six pregnancy tests to make sure that the result was accurate. Scott was shocked and he buried his head in the sand at first as it all happened so quickly. The next stage was letting their parents know. Scott's parents-in-law lived in Lincolnshire and his parents lived on the Isle of Wight. They were pleased to hear the news and were delighted they were going to be grandparents. Scott felt it would be wise to tell social services and his partner's social worker about the pregnancy; they took the news well and were supportive.

Antenatal care

At the booking appointment with the midwife, Scott's partner was immediately classed as "high risk" because she had a learning disability. The midwife did not explain what she was at high risk of, just told them "we do that for all vulnerable people". This made Scott feel very nervous. They did not see the booking midwife again.

The midwife Scott and his partner saw next time understood their situation better, as she herself had a child with learning disabilities. She became their named midwife. She understood where they were coming from. This midwife told Scott and his partner that she could not see a reason why they would not be able to parent their child. Scott felt this was positive.

The first part of their antenatal care went well in terms of information giving. However, it was given in a non-accessible format, with lots of medical jargon and was difficult for Scott and his partner to understand. They voiced to their midwife that they needed information in an accessible format. The midwife said that the hospital did not have the information in this format and the only place to obtain accessible information was from the organisation Change, which would charge Scott and his partner to purchase it. Scott explained that this was not good enough and they needed the hospital to give them information in a way they could understand. Eventually, the hospital did give them accessible information. The midwife also gave them helpful practical tips to get the equipment together at home for the baby's arrival. The midwives were impressed that Scott and his partner were so prepared and gave them additional support to demonstrate how to use the equipment. Scott and his partner felt prepared to have the baby at the end of the pregnancy.

Scott feels that the issues started for them when their named midwife went off sick. The midwife they saw going forward did not understand them. They had to start from scratch explaining their situation and their needs. The midwife assumed that no reasonable adjustments would be required for the birth, whereas in fact reasonable adjustments could have had a big impact on their care and experience. Scott said it was difficult to get across their needs. For example, the midwife gave his partner a tour of the maternity unit to help signpost where to go in labour and promised that she was going to be present at the birth. However, when labour started, the midwife was not there. They assumed that they would have continuity and felt let down in labour.

Scott and his partner were referred to the safeguarding team for a "best interests meeting". Scott questioned why this meeting was taking place before the birth of the child. Scott felt that the safeguarding midwife ignored him during the meeting, she did not acknowledge him and focused only on his partner. This soured their relationship from the start. Scott said that they should have been treated as a family unit. Scott's partner needed support from him, they were in this together. Scott also felt that the safeguarding midwife couldn't make the reasonable adjustments to care they needed.

Intrapartum care

Scott's partner had a bloody show at 4am. Scott phoned the triage unit to inform them as neither Scott nor his partner knew what it meant. They had not been told it could happen. Scott wanted to take his partner to hospital. The midwife on the phone said, "yes, but you will probably be sent home". The midwife asked how much blood there was, but Scott couldn't answer accurately as it was in the toilet bowl. The midwife told Scott and his partner to come in. They had to get a taxi which was very expensive.

Scott's story (cont.)

Once in the triage unit, the midwife assessed Scott's partner and concluded that it was Braxton Hicks and early labour; they said she would be better going back home. Scott and his partner got the bus home as it was now morning and buses were running again. Scott was due into work and called to say that the baby was coming soon so was able to start his paternity leave that day. Throughout the day, Scott's partner started to become more distressed and to scream as labour progressed, disturbing the neighbours. Scott called the hospital again and explained that she needed to come back in. They got another expensive taxi back to triage.

Once they arrived in triage, it was three hours before Scott's partner was assessed again. She was in distress the whole time. The midwives said she was still in early labour and needed to go home. Scott said she cannot go home in this state. Scott was frustrated by the situation and left the unit to get some food. Whilst he was out, the midwifery team reviewed his partner's progress and called Scott to enquire where he was. Scott said that she needed to stay in hospital as that was where he felt she would get the best care. Scott felt that the maternity team did not like his response, and thought he was being irresponsible by not being present at the review. Scott felt that if he had not gone out of the hospital, the midwives would have forced him to take his partner home where she would have been distressed. So, he felt he had to leave in order for her to not be sent home, as the midwives would not send her home alone and so she would be kept in where she would receive the care she needed.

Scott did not go back to the unit that day. His partner stayed overnight but they talked on the phone a lot, both felt very emotional about the situation. Scott arrived at the maternity unit at 7am the next day and at 9am the decision was made to induce the baby due to the prolonged first stage of labour.

However, the induction did not start until 3pm that day, so Scott and his partner waited around for six hours, all that time she was in distress and pain. The midwives said that it was due to no capacity on the labour ward. Scott was crying as he did not like to see his partner in pain. The midwives gave her a TENS machine and Entonox but it was insufficient for her pain. She did not eat when food was offered as she was in so much distress.

Once the induction had started and Scott's partner's waters were broken, Scott felt the midwives were observing rather than intervening to get the baby out and he did not understand why; it made him question the care. Scott was crying as he could not cope anymore, he didn't feel he could fight anymore to make sure his partner received the care she needed, all the while watching her go through distress and pain.

Eventually Scott's partner had an epidural and was more comfortable. Scott overhead one of the doctors in the corridor saying "[Name] is screaming the hospital down, we need to get that baby out". This was when his partner had received her epidural and was no longer screaming in pain. This made Scott question the care that his partner was receiving and why they needed to deliver the baby quicker. Scott felt very upset as he could see that the staff did not understand how someone with Autism would experience labour.

Scott's partner delivered their baby vaginally and he was relieved and happy. Scott went home later that day. Whilst his partner was sleeping, the midwife took the baby away without telling her that she was going to do that, as the baby was fussing, probably with the intention to give mum some rest after the birth. However, Scott's partner woke up to find her baby gone all of a sudden. That was very scary for her and Scott.

After the birth

The safeguarding midwife had visited Scott and his partner on the postnatal ward the day after the birth for a "team around the family meeting". Scott's partner wanted to breastfeed, but felt the midwives observed, rather than practically supporting her to learn how to breastfeed. The safeguarding midwife said: "You can just bottle feed, Scott can go down the supermarket and buy the milk". Scott felt they had no choice. As a result, his partner ended up bottle feeding which was not her preference.

The safeguarding midwife asked about contraception. Scott's partner said that they did not use condoms. The midwife responded, "we will just give you the Depo injection". Scott felt that his partner thought she had no choice and had to accept what the midwife told her to do. The midwife did not explain the different types of contraceptives available or involve her in reaching an informed decision.

The safeguarding midwife also asked lots of questions, including "what would you do if the baby was unwell?". Scott answered that he would "call the GP or take her to A&E". The safeguarding midwife told him that his response was wrong, and that instead they should call the "midwifery team". Scott felt that his responses were sensible and not wrong, but she made out that he would not be able to look after the baby properly.

Scott's story (cont.)

Preparing for discharge

Scott's partner had been in a side room during her stay on the postnatal ward. However, on the night before she was due to be discharged home, the midwifery team decided to move her to a bay in order for her to "interact with the other patients".

Before she was moved, the midwife on the dayshift suggested to double the baby's milk quantity for each bottle feed. This made the baby distressed overnight with possible colic. The midwife on the night shift questioned Scott's partner as to why she was giving the baby such a high quantity of milk, she explained it had been suggested by the dayshift midwife. However, this was not documented in the notes. Scott's partner felt that the nightshift midwife did not believe her despite the fact it had been said in front of Scott and his mother.

Unfortunately, this made the baby very unsettled, crying a lot during the night and disturbing other mums. During that first night in the bay, Scott's partner was accused of shaking the baby whilst trying to console her. They were not told who had said they observed it or when they said it had happened during that night. Scott thought perhaps some of the other patients may have complained about the baby crying to the midwifery team, who then felt that Scott's partner was not coping with a crying baby. This was understandably very upsetting for Scott's partner to hear. Scott was at home the following day (discharge day) getting the place ready and clean for when his partner and baby came home. His partner called to tell him what had happened, and that the midwives said they were going to put a referral into social services, but that they were allowed to take the baby home today as planned. Scott questioned this accusation as if the safeguarding team felt that their baby was in danger of being shaken, they wouldn't let them take the baby home that day.

Scott's partner's support worker came into hospital that day to take mother and baby home to Scott, who was waiting at home. The safeguarding midwife saw the support worker in the corridor and shouted sensitive information across to him, within earshot of two bays full of patients. She shouted, "[Name] is upset that we think she will shake the baby, and we have put a referral into social services". This was humiliating for Scott's partner to hear, as the other patients / partners / visitors were now aware of the accusation.

At home

One week later, children's services visited Scott and his partner at home. Lots of people attended this meeting: Scott, his partner, her support worker, the midwife, a family centre representative, and children's services. They informed Scott and his partner that the midwifery team felt that they could not cope with looking after a child because they had learning disabilities. Scott said that felt horrible to hear. He was also going through his father being seriously ill in intensive care in London, who he needed to visit urgently on the mainland, but he felt he could not disclose this to the team as that could make things worse.

In the meeting, Scott asked whether the team had heard of the government white paper which talks about how people with learning disabilities have a right to have a family, a job and to live independently. They replied, no, they hadn't. Scott advised them to read it. Scott also informed them that he is the co-national director for learning disabilities, representing policy and promoting the right to be independent. Scott reinforced that he is capable to parent his baby. The team said that they still needed to do an assessment, which they did.

Six weeks later they had another meeting and the decision was reached that Scott and his partner were parenting the baby to the best of their ability and the case was closed. Scott said that for the first six weeks of their baby's life, they lived under constant scrutiny as a result of an accusation made on the postnatal ward. This affected their physical and mental wellbeing, as well as how they bonded with their baby.

This story was told to Together Project researchers by Scott. We are so grateful to Scott for his bravery in sharing his personal story.