



Families

Organisations

Professionals

Reliability



## Birth Injury, Disabling Families & Enabling Human Factors

Dr Dawn Benson (2014)



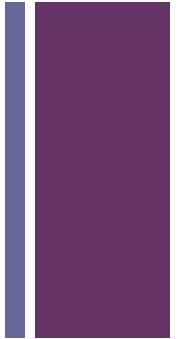
# Background

- I have parented nine children including four disabled children and two children who were in the looked after system and I came to this research expecting parents to want to focus upon the things which bothered me such as relationships with statutory sector professionals and services. I also came at the research as a parent of a child avoidably injured at birth and having completed a clinical negligence case as his litigation friend (see is picture on the front slide). As I expected, parents did want to talk about the ‘disabling reductive constraints’ of living in a family needing to access specialist services for disabled children and ordinary life in an inaccessible society but more than that they wanted to talk about the birth injury event. This study covers the questions which I started by asking (see below) and it went much further to explore why things go wrong and what health care providers need to do if they want to reduce or eradicate avoidable birth injury.

1) Why pursue litigation

2) Relationship with professionals before during and after the litigation – they wanted to focus upon and they the birth injury event.

- **This study is about:** - Families, Professionals, Organisations and Reliability notions of reliability came from the parents who, in the process of building resilience after birth injury and their own life experiences as a disabled family, come to exemplify the characteristics expected of High Reliability Organisations.



Track small failures

Resist oversimplification

Sensitive to operations

Maintain capabilities for resilience

Take advantage of shifting locations of expertise



Mindfulness

Capability to  
Discover &  
Manage  
Unexpected  
Events



Reliability

Adapted from Weick et al,  
(1999)

# High Reliability Organisations and Medicine



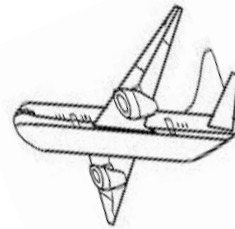
HROs expect the unexpected – expect and design systems and technology to mitigate against the Human Factors which often lead to error. Typical HROs are:

Aviation

The Military

Formula 1 Racing

Nuclear Fuel



For every 300 people who seek medical attention 30 will experience an avoidable adverse event 6 serious and 1 fatal - in perspective that equates to between 23 - 30 Jumbo Jet crashes a month un the US, 6 across the UK and 2 across Australia.

Amazing there are not more personal injury solicitors – largely because when things go wrong in aviation or other HROs they are magnified by the volume – in medicine the incidences tend to be unrelated and if they are it takes someone to make the link. Catastrophic events with other HROs are therefore easier to learn from which is what the parents wanted to happen from their experience.

# About the Participants

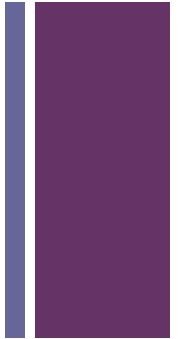
**Participants included 7 mothers and 2 fathers. They were all very different yet they share some characteristics which were immediately noticeable:**

- All but one of the injured children were the mother's first born child
- All of the critical incidents which took place in a maternity setting did so across the weekend period
- Three of the families made contact with their solicitor through AvMA
- All but one of the parents used English as their first language
- Two of the fathers left their jobs and became full time carers for the disabled child
- Five of seven families (including mine) moved to adapted accommodation following the completion of litigation.
- Other than myself, who had no formal education at the time of initiating the claim, all of the families had at least one parent who had a minimum of a university degree or professional equivalent
- The children had collectively attended a mix of mainstream, segregated/'special' schools and mixed placements and shared a sense that their education was fluid and could change at any point depending upon resources

**Beginning:** Birth injury incident and its aftermath:  
an accident waiting to happen

**Middle:** Re-establishing a sense of control:  
families seizing control

**End:** Negotiating roles and fighting for  
ordinary: living in a goldfish bowl



# Themes

- Why parents pursued litigation
- Finding & changing solicitors
- The litigation process
- Messages to legal teams
- The role of the deputy
- Messages to other parents

# WHY PARENTS PURSUE CLAIMS

- **Different reasons** at different times in the process
- Wanting **answers** about what had happened, finding out the truth
- **Protect others** – make sure it does not happen again
- Being angry and wanting **resolution**
- Wanting to be **financially independent of the state** for support services



# Different Reasons

Bob: Anger I was thinking about it as I drove home – I didn't think of litigation I just wanted revenge, later I wanted them to acknowledge what had happened.

Janet: I look at it from a different angle when I wanted to go down the litigation route it were to see what support we could get.

Janet & Bob – Interview data

# Answers

It was more about finding out what had actually happened. Because, you know, nobody seemed to know or have an idea about what had happened.

Sophie – Interview data

# Protecting Others

They were still saying this could have just happened – it could just happen again

Clare – Interview data

We wanted to make sure it wouldn't happen again, apparently the hospital changed the policy as well and they monitor as a routine and ok so it's benefiting other kids. Also I knew that it would take a lot of money to give him all the things he would need.

Sophie – Interview data

# Resolution

I remember the day the solicitor said 'it's more or less settled'. I was not happy – I would have coped better if I had know that he was born with some difficulty – even what ever as opposed to negligence which is inflicted and changed his life and it changed our lives but not like his life. You might say well he does not know the difference but he was not given the choice to know the difference. I knew that sorry wouldn't mean anything and I got the letter when he was 8 years old and it didn't mean anything and even with the case settled it didn't mean anything and because you know that day-to-day life is the same... apparently the hospital changed the policy as well and they monitor as a routine and ok so its benefiting other kids.

I've asked time and time again, 'can I see the results of this thorough investigation'? No, that was the legal team; 'you're not privy to those'. Nothing, they just said you know things went wrong, and not been told, time and time again, Steps have been taken so that it will never happen again but what steps, specifically, give me an answer? We've never been given a specific answer and that's one of my biggest regrets because actually that's one of my reasons for pursuing the clinical negligence claim, was that we could get some answers, firstly what happened and secondly to stop it happening again and as I say that's one of my biggest regrets. I don't feel we achieved anything in that respect. We insured her future with the claim, we ensured she's got money to provide for whatever she needs for the rest of her life but I don't think we made any progress in getting any answers or changing anything for anyone else, which I had hoped – maybe naively.

Susan –Interview data

# Financially Independent of the State

They didn't admit liability for it for 7 years and it wasn't really until a long time that I'd got over that huge anger and thought, you know, actually we need this because the only thing that keeps me awake in my exhaustion at night is, God, what's going to happen to her when I'm dead, you know that – I think it wasn't really until a long time later that I could actually think I need to have this. You know, she needs to have all of this in place so that she's got somebody looking after her finances and somebody that will provide for her for the rest of her life.

Clare – Interview data

# FINDING & CHANGING SOLICITORS

- Contacting a solicitor was part of **regaining control**
- Parents were usually **encouraged by others** to seek legal advice
- **Stumbling across** the right solicitor
- **Continuity** was rare through the process

# Regaining Control

I wanted it soring out.

Bob – Interview data



# Encouraged by Others

In conversations with staff in special care ... there was defiantly a view that they weren't terribly happy about the delivery and partially helped by the fact that my father in law was a GP who had talked to the consultant so we knew at a very early stage. My parents were asking Questions, my husbands parents were asking questions and my dad pretty soon contacted AvMA to find out what we should do next. My community midwife was also fantastic because she came the day I got home and took a statement and sent stuff off to AvMA and they sent it to a solicitor. AvMA were really great – the whole thing of having somebody look at your records and say yes you may have a case here.

Sophie – Interview data

# Stumbling Across Them

I spent an entire morning ringing round our town to find a solicitor. That could take our case. It was a conveyancing solicitor who said have you tried ... in the city and so I did.

Bob – Interview data

I was a solicitor at the time. I didn't do clinical negligence, I did something completely different, but that may have eased access for me. You know, it wasn't a big step for me to phone a friend and say, "I need to come and see somebody at your firm.

Clare – Interview data

# Continuity

I remember the day the solicitor came out to see us, we went through a local solicitor and they kind of started reviewing the paperwork and then I started doing a bit of research and I said to (husband) I'm really not sure that this is something for a local solicitor to be taking on. We got in touch with AvMA and they had a group of solicitors that they recommended.

Susan – Interview data

It started from legal aid where we got the name of the first solicitor who did medical negligence and she left that firm and joined the one that we stayed with. We had a choice to stay with her and go to new firm or stay with old firm, we went with her then she left there and we stayed with another partner.

Alysha – Interview data

# THE LITIGATION PROCESS

- The litigation team provide them with often much needed **reassurance** that they were doing the right thing
- Parents found that in their interactions with professionals they often needed to **protect their own autonomy**
- The process was like **living in a goldfish bowl**

# Reassurance

I think our solicitor was really good, he was absolutely superb, because he was positive. He was positive that we had been right to go to him. He thought there was a claim there, that we had done the right thing. He was able to deal with two totally different ends of the spectrum in respect to Janet coming in a state of denial, upset, devastation, and me coming in as angry, revenge, resentful. He'd got every emotion he could physically think of in that room at that time and he just dealt with it. It was just reassuring to know that he understood where we were, he made us believe that we were doing the right thing.

Bob – Interview data

# Protecting Autonomy



I think I felt completely out of control, and I felt like everybody else was saying to me, “Right, this is a tiny, little box that you live in now...” that’s a funny way of explaining it, but that is exactly how I felt. I felt, you know, you’ve got this little box – these are the parameters of your life, and you will live in those and we are all going to come in and tell you what you must do, all day, every day.

Susan – Interview data

The other side's technical expert came in and said "Oh, you know, I think that you are overly bonded with your daughter and you need to set some boundaries and some distance." I really felt like I wanted to stick two fingers up at them and tell them where to go. But, you know, I didn't. I sat there and smiled politely and said yeah, this is because Just so that you know why I'm overly bonded with her, is because one of us sleeps with her. She has epilepsy. We know she has constant seizures when she's asleep from her last EEG, and I know too many children that have died, I don't care if you think I'm overly bonded with her...

Clare – Interview data

Janet: The case manager said to Bob, “Really, should you be doing personal care for your daughter?”

Bob: Absolutely, she made me feel like shit.

Janet: She made you feel like a pedophile.

Janet & Bob - Interview data



# Living in a Goldfish Bowl

It's just such a good example, isn't it? Of the loss of...I want to say loss of privilege, but it's the loss of your rights that you endure through this process because, you know, I mean I felt like... well, an unknown number of people out there knew so much about me. You know, I thought they knew when I went to the toilet. Because, you know, it was all in writing everywhere. Everybody knew everything. And I hated it...as a private person I really disliked that so much. I found that really, really hard.

Clare – Interview data

# MESSAGES TO LEGAL TEAMS

- Expert witnesses do your **homework**
- Minimise the number of **appointments**
- Show **Empathy**
- Parents also experience **harm**
- Our home is **not a place of work** or a project
- **Inclusion** by putting us back to or as close to the position we would have been in had it not been for the injury

# Experts Should do Homework



I had to tell it so many times that I just sort of - it also means you have less closure on it cos you're constantly having to tell the story over again. Do they really need to know this, three speech therapists do they really need to know about his birth? It's the endless going over.

Victoria – Interview data

The part of the process that I absolutely used to hate was having to go over the birth with every expert. And reiterate everything. It was like it was stamped into your mind. I could go there and rhyme it off parrot fashion without even opening my eyes. I knew what was going to be asked and that's the only bit that really got me down.

Janet – Interview data

# Appointments

Traveling up and down the country to see different specialist who treat you like second class citizens. One of them talked to Janet like she were a 'man servant'.

Bob – Interview data

The amount of time spend doing assessments, well it didn't warrant it. We both needed to take a couple of days off work each that's four days pay lost and then we needed to take her little brother and stay in a hotel

Janet – Interview data

# Empathy

They came into this very room. “*Oh, hello, lovely to see you. Congratulations.*” And I just felt it was so inappropriate, because, really? What – congratulations they’ve admitted that somebody was wrong and ruined my life, you know?

Clare – Interview data

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I think that to a lawyer, I think the thing to try and have a mindset that yes, you are the legal person, either fighting the NHS or dealing with private client financial matters...but go and meet the family. I insisted that everybody came and met her. She can't talk, and she's got no idea who they are, but I wasn't looking at it from her point of view. I wanted them to meet her. This isn't just another case that you're...this is somebody's life. And I think the importance of recognising that this is a devastating trauma that's happened to this family. And might be your bread and butter and what you do every day to earn your money, but you need to come and recognise and really think about...this is a broken family that you're dealing with and you need to keep that in mind. And I think that's the important thing that I would say ... you are dealing with people who are at their utter, devastatingly worst. You know, this is probably the worst thing that has ever happened and will ever happen to this family, keep that in mind every time you pick up the phone, don't just say, "Oh, I must just phone up Mrs. X and ask her why she hasn't looked at her statements yet." You know, think about it

Clare - Interview data

# Harm

It changes who you are, Yeah, I mean, I'm certainly not the person I was. You know – when I had her I was a very different person to the person I am now and I feel like the shell of the person that I was...

Clare – Interview data

...it all made me think about not ever trusting anyone to look after him, I think I am like my friend....who, her daughter was starved of oxygen and they used the same solicitors as us. She is very overprotective and can't let other people do the looking after. I think I am like her and it's strange that other parents for special needs kids aren't the same; maybe it's just us after we have been through this thing. We can't trust anymore... I am in a permanent state of anxiety.

Alysha –Interview data



# Our Home is Not a Place of Work

Whilst it is my home, it is unfortunately a working environment. But you really do have to strike a balance, don't you? You know, shall I put one of those clocking in machines and have them clock in and out in the hallway as they come in? You know, you do have to accept that... They might not want to wear shoes or whatever else. And she was quite odd. And, as I say, it shouldn't even be funny. But you have to – I suppose you have to find the humour in it, don't you? Otherwise you would go mad. Oh, do you know, we had this real hoo-hah when we had the bathroom adapted about the need for a second sink for them to wash their hands in.

Clare – Interview data

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we'd searched the area and this was the only house that was ever going to be anywhere near big enough with sufficient space to do what we needed to do. There was no plots of land, nobody was willing to build us a bungalow. If you built a plot of land big enough for the size bungalow you needed, they could get 6 houses on there. So there was no way that they were going to sell you a nice, big plot of land when they could put 6 boxes on there and flog them off at the same price as the one bungalow. So we found this, didn't we? Let them know – and two years later... Literally two years later, they then employed a specialist house search solicitor – or whatever she was... Her job. And she went and saw in the region of between 5 and 10 houses per day for about three weeks, to come up with the findings that this house was the only one that was big enough. And then we got it, didn't we? But they physically had... You know, it was like... Was our word not good enough? You know, we're not thick. We both had managerial jobs. We know pretty much what we want, what we need – you give us the brief of what we've got to get, and we know this area a damn site...

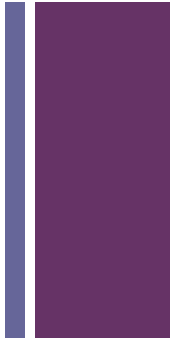
Bob –Interview data

# Inclusion



I still feel now that a lot of the so called experts writing the report are writing from a medical model still and that they don't actually fully comprehend the whole picture of how all of the fits in. The experts who are involved in quantum they need to learn what its like caring for somebody. I still feel that a lot of it came out of blinking textbooks and wasn't actually based on what we should be expecting disabled people to achieve with proper support.

Sophie – Interview data



I wish the systems were different and that you didn't need a claim to be able to pay for things that should be paid for anyhow. I shouldn't need a clinical negligence claim just to give my daughter what she needs, that should just be available, but it's not...*society will never change to that degree. It will never be that inclusive, and so that, I suppose, you know, some of your compensation is to try and make your small society – whether that's just in your house, in your car or wherever – as inclusive as you would like all of society to be.*

Clare - Interview data

I got really annoyed throughout the claim at the game aspect of it and to the solicitors they almost, in a funny kind of way enjoyed this element of the game, even our solicitors. To them it was them kind of doing their jobs and at times I got really upset and they say well that's just the way they play it. I say I'm not playing a game, this isn't a game to me.

To them, it really was. They'd be like, but that's just to be expected. It's like, well it might be to you because you do it day-in-day out, this is your job. I've never done this before so I wasn't expecting this, we were told that we need to over egg our claim we were told 'you always ask for more than you want because you're not going to get it, and if you ask for what you want you're not going to get it so you ask for more than you think you're ever going to get because they're always going to knock you down.

can't we just sit around like sensible human beings and talk about what we really need? Yes be honest, not over egg this end and over egg that end, then meet in the middle. Let's cut all that out.

Susan– Interview data

# THE ROLE OF THE LEGAL DEPUTY

- **Guidance** about how they can use the award to maintain their lifestyle choices
- **Support in accessing services** such as social care and education
- Parents need **advocate not managers**

# Guidance

He said, “Oh, you know, well, you’ve got the such-and-such set aside for carers.” Which is good because he said, “I really dislike these families where the fathers give up work and become a full-time carer.” And I thought, “actually, that would be ideal because I hate having people... No matter how pleasant they are, in my house at 7 o’clock in the morning and feeding and dressing my child because I can’t, apparently.” You know, or... that’s probably a bit too dramatic. You know, obviously the carers are there to help and assist but actually it is really, really intrusive, having somebody here all the time that I’m awake, pretty much. And I just thought that was a massive lack of understanding.

Clare – Interview data talking about her encounter with a judge at the Court of Protection

# Support in Accessing Services

- Significant differences between parents in what they believed they could and should do with their child's money
- Many parents were frightened to spend money
- Parents often did not know their rights in terms of education Law and Peters Undertaking and were being refused services
- Preparing for the future is something which Deputies could be helping parents to do.
- Deputies hold valuable sources of information about products, services and professionals but there is little evidence that they share that information with families



# Advocate not manager

It wasn't a good relationship at all...the solicitor sort of said, "Right, okay, so we need a deputy now - we use this woman." ... and we went, "Okay", ... if we wanted to buy her anything we had to almost apply that's why we changed deputy. After we...realised we weren't getting DLA anymore, yeah, and she hadn't even told us...you know, and I said to her DLA is a living allowance, this is money I use. She doesn't walk, she crawls, she gets through clothes at an amazing rate because she just wears them out ... I don't want to have to tell you every time. So in the end it got to a point where I sent her a very vivid email. (child) had diarrhea and I had literally cut her clothes off her and thrown them away. So I explained in great detail why I needed some money to buy her some new clothes, and it was at that point that our relationship had completely broken down. So we went to a different deputy... It's a much better relationship with the new deputy and for us it's working at the moment, she has said, you know, if at any point either one of us want to be the deputy, she would actually support that.

Clare – Interview data

# MESSAGES TO OTHER PARENTS

The advice to anybody else going through litigation is find somebody else that's been through it. I had somebody else and although we didn't talk about it very much. There is one or two people on the message board who ask questions and I send messages to. Having somebody else to talk through the process is useful. It also depends which stage your at.

Victoria – Interview data

# Characteristics of the parents

1. Looking for and tracking small errors
2. Vigilance & avoiding complacency
3. Conscious of critical edges of practice
4. Responding to opportunities for personal & professional growth
5. Readiness for shifting paradigms of expertise

# Looking for and tracking errors

## **Messy interface between the social and medical models of childbirth**

I did both the NHS and NCT anti-natal classes and they were all about this lovely natural birth experience with calming music and things, which for so long was the case, but then 'boom' switch to natural disaster. None of it prepared me for that.

Victoria – interview data

I did the NCT classes at the hospital and I did the yoga classes, so yes I was fully prepared for anything - except for what actually happened.

It never once crossed my mind that what happened would happen. It never entered my thought process. And I'm quite an analytical person and I consider the risks of most activities. In an ideal world I would have had a homebirth....I had accepted in theory that we would be safe in hospital; in my head that is where it stopped. I'd made the decision; I was going to the hospital. To me, I wanted this natural birth. I had it all planned out in my Birth Plan. It was going to be a lovely natural birth and to me the worst case scenario was that it would go wrong and I would need a Caesarean. Nothing prepared me for what happened.

Susan - Interview data

# Vigilance & avoiding complacency

## Preoccupation with breastfeeding

They didn't listen to me. I kept saying on every shift change 'he is not feeding well' and there was this midwife that insisted 'you have to breastfeed, breastfeed'. The problem was, he was born with low blood sugar but they didn't treat it. They told me that he was low blood sugar – that he needed feeding but they didn't do anything until it went ... well until he was dying. They kept insisting that I had to breastfeed, not even bottle milk you know nothing only breast.

Alisha – interview data

# Conscious of critical edges of practice

## Situational Awareness

My husband having been in labour with me before was able to recognise established labour and he would tell them [we were worried] but they did nothing. Then when I got to the stage when he knew that things were moving on further again he was ignored. We obviously don't know what else the midwife was doing because she probably had more than one person to care for. .. As a health professional myself I know that you can't do everything. But her attitude wasn't helpful

Sophie – interview data

They were too busy, no one was really giving enough attention to realise that there was a problem – they weren't seeing the whole picture.

Bob - interview data

The nurses are too frightened of the consultants and the anaesthetists are too frightened of the surgeons and the hierarchy is dangerous cos it stops people from communicating and breaking a fixation with an idea that might be wrong.

Janet - interview data

# Responding to opportunities for personal and professional growth

## False economy

As soon as the drip was set up, my contractions went wild - it was just like one continual contraction and she (baby) went into severe distress...they were then giving me injections to stop the contractions altogether...the registrar came back to check on me and said a Caesarean was needed ASAP. However, at that point there were three women needing a Caesarean...he made a decision - and I don't blame the registrar - he made the decision to take one of the other ladies first and me second and the third lady third. I don't believe he made the wrong decision because I think had he taken me first there was a good chance that if number one went second, she would be sat where I am. A decision had to be made - I haven't got access to enough information to know - he possibly did make the wrong decision but there were three women needing a Caesarean and he just had to pick basically. I've been sat there waiting for a Caesarean for an hour and it hadn't happened. All the time, they were watching the monitors and I kept saying to them - and I remember so clearly lying there, and the room was full of people, full of people and no one could do anything. Everyone was just stood around looking at each other and it was the looks on their faces, you could just tell. Nobody was saying anything - and I kept saying is the baby all right, is the baby all right - and they kept saying, the baby needs to be born and yet we didn't do anything. They couldn't do anything. There was no doctor, there was no theatre, there was nothing anyone could do. They were just midwives, they were just monitoring a deteriorating situation.

This is where the cost-cutting comes in - because when I said 'why not have the obstetric theatre staffed every day?' They turn round and said, it's not cost-effective. I kind of just lost the will to live at that point, it had got to be more cost effective to provide the staff than pay for litigation. The obstetric unit wasn't in use because they don't use it on a Sunday evening.

Susan - interview data

# Readiness for shifting paradigms of expertise

## Hierarchies

It's not right but that's how it is. You're in hospital and you do as you're told and the nurses and junior doctors are all kowtowing down to these superior beings (consultants). You know, they put these people on a pedestal and at the end of the day they're the same as anybody else – they just get paid more for doing what they do. The junior doctor knew there was a problem but either he wasn't assertive enough or the consultant wasn't listening properly.

I was 42 weeks pregnant and I went in on a Saturday morning to be induced. I was in labour for over 30 hours. They were recording the contractions and I had an epidural and they picked up that the fetal heart wasn't coming back fast enough after a contraction so they did three arterial scalp bloods and each time they did the blood gases had dropped. Our consultant because it was weekend wasn't on duty (my italics) and so the midwives and the doctors called him. He was playing golf and he said 'continue taking arterial bloods' – this was by Sunday afternoon. I kept saying all along that I wanted a C-section. Once the decision was made to do the cesarean section I had to wait for the anaesthetist who took 25 minutes to get from the other side of the hospital.

Janet - interview data





# James Reason's Swiss Cheese Model

'trajectory of accidental opportunity' (Reason, 1990)



## 1 Defence barrier

The GP Obstetrician attempted forceps out of theatre and cut the cord thus depriving the baby of oxygen. Reason would describe this as a 'violation or deviation from safe operating procedure'

## 2 Defence barrier

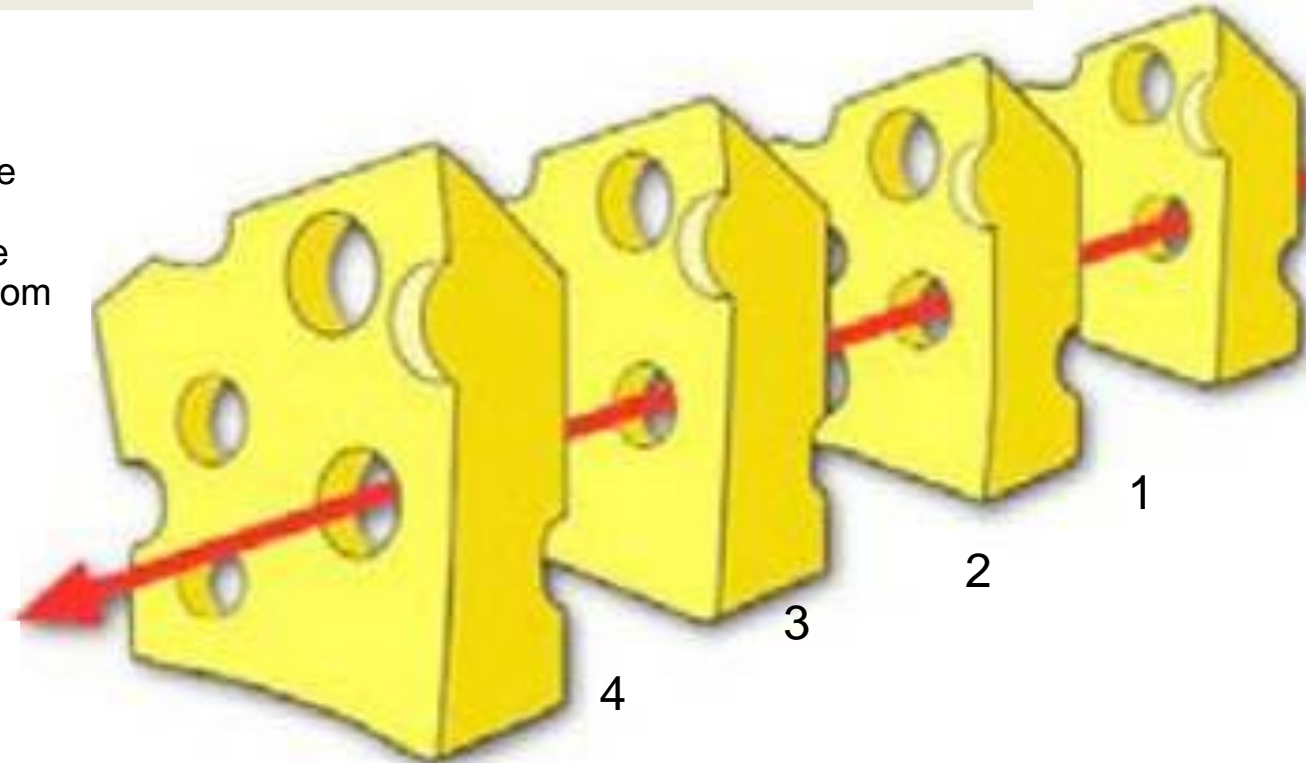
None of the midwives attempted to prevent the doctor from carrying out the procedure

## 3 Defence barrier

The anaesthetist was not on site

## 4 Defence barrier

None of the attending staff were skilled at resuscitating newborn infants



Victoria's story

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Slide 4 aviation/medical error data is taken from

- Catchpole, K. (2012) Why Medical Error: Ted talk[<http://www.youtube.com/watch?v=u6VuaxC0m5I>]