

# Invisible and centre stage: a disabled woman's perspective on maternity services

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## Invisible and centre stage: a disabled woman's perspective on maternity services

This paper is based on a presentation made to the Department of Health Open Forum Event of the Children's National Service Framework (Maternity Module) in January 2003. It is a disabled woman's experience of pregnancy, birth and the maternity services.

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This time last year when my daughter was four months old, I carried her strapped to my front in a sling. I went out and about with great regularity, displaying new baby and new motherhood and wheeling proud, and whilst there would be some clucking, mostly what I received were slightly odd looks. On a particular day we were at the newsagents, a shop I'd been using for at least a couple of years. At the till, the woman who'd worked there throughout blurted out "Oh god, it's a baby! I thought it was a teddy bear."

When I was pregnant, it was not much different. In my ante-natal class, one woman wondered aloud whether everyone was approached by complete strangers asking when it was due and they all nodded and laughed in recognition. But, no. Not once did it happen to me. Hugely pregnant, I would go into John Lewis and still people would say "What a lovely wheelchair" and "How does it work?"

It seems that people struggle to see me as a mother or a potential mother. And, given this fundamental perception that, as a disabled woman, I cannot be these things, then it's no wonder when it comes to maternity services, I'm on the outside.

This paper is my personal perspective on maternity services and I have to admit that my happiest recollections of pregnancy and childbirth are when maternity services and I were apart.

Below, I tell you about some of my experience of pregnancy and birth. A brief background to this: I am a full-time wheelchair user and a part-time employer of personal assistants who provide the assistance I need with various aspects of daily living. This was my first pregnancy, long awaited and keenly sought. Labour began as a home birth with a birthing pool, later becoming an emergency transfer to hospital and a caesarean.

I will use my experiences to illustrate a set of guidelines for you to use in your own work in maternity services, whether this is developing policy or working with individual women.

Some of my experiences were good and I will include them here, but the majority were hard graft. Whatever the truth, I was perceived by professionals as the first pregnant disabled woman and the response was largely one of un-ease, even

panic. There's a conundrum in my experience, because if, as a disabled woman, I was largely invisible in policies and working practices, as soon as I was noticed, I became centre stage. At the time, I wrote in a journal: "I want to be a pregnant woman - not a problem, not a phenomenon".

So here are my guidelines.

### **Guideline 1: Relax**

Do not feel threatened – diversity is a good thing. Without diversity, we grow stale and we limit the range of imagination, of possibilities and contributions. Do not feel threatened, because people are both different and very much the same. My perspectives, experiences and strategies are tied in to being a disabled woman, but my days now are filled with the standard fare of motherhood: I change nappies, do piles of washing, go to the park, I give and receive cuddles and of course I *know* that my baby is as good as it gets.

When I am on the outside needing to get in, what I see is a lot of people missing the point. My being on the outside is not about me, but about them. It's about the assumptions and the ways of working that exclude whole groups of people. Tackling that exclusion, by introducing inclusive practice, is not about making 'exceptions' or meeting 'special' needs. (It is only when they are not provided for that needs become special.) In maternity services, inclusion is about achieving a state where I can primarily be *pregnant* – not because I am the same as non-disabled pregnant women, but because my needs are just as integral to planning and working practices as theirs.

I still aim to believe in a world that will work towards this simply because it's the right thing to do. But even where that's absent, we are talking of public money, public organisations, public employees, all existing to serve the client group. And, with the Disability Discrimination Act, which has been around since 1995, despite appearances, inclusion is no longer a voluntary exercise<sup>1</sup>.

### **Guideline 2: Decide to become inclusive**

Make it your starting point and an absolute requirement.

From early pregnancy, I hoped for a home birth. As for any woman, I knew that nothing was guaranteed, so I visited one of two local hospitals to check on facilities. The staff were kind, but I was dismayed. I would not be able to lift my own baby from the cot provided, all meals were self-service, the only accessible loo was down several corridors, and there was no accessible bath or shower. After how ever many hours in labour I would be unable to wash and would be expected to use a bedpan for several days. The clinical environment, with hospital beds and surgical trolleys, left me overwhelmed by years of medical experiences and my worst fears of hospitals.

### **Guideline 3: Think of the impact**

Remember that the impact of maternity services on an individual is affected by their experiences and circumstances.

So I visited the other hospital and the experience could not have been better. This time I was welcomed to a newly refurbished delivery suite – it felt unclinical, there was an accessible loo, hoists were on tap, and there was a wheelchair accessible room on the post-natal ward. Best of all was the greeting: I was listened to by the midwives, offered suggestions and ultimately not required to apologise for anything.

#### **Guideline 4: Talk and listen**

Recognise people's experience and expertise, often hard-won. These staff knew that I was the expert on my own situation.

If you are looking for a way into these conversations, the birth plan was very useful for identifying my needs and thinking through solutions in a very practical way. It would have been even more useful introduced early in my pregnancy and could have been used as a planning tool, not just for labour but throughout ante- and post-natal care and by a range of professionals and support workers.

But back to hospitals. Hospital two, with its excellent physical access and welcoming approach, was a role model of how to get it right – until the post-natal ward became involved. They refused to admit my personal assistants on grounds that 'visitors' were not allowed outside set hours. I was told that midwives would (apparently) meet my access needs throughout my hospital stay and that there was no room for negotiation on this. Having just given birth, I would be faced with the prospect of training a random set of PAs on the intricacies of my personal needs. The hospital made no attempt to find solutions, but expected me to 'fit' their facilities and routines. Until two weeks before my due date, I had no hospital cover at all. If I had gone into premature labour or had a medical emergency, neither hospital could have given me adequate medical care.

When I wrote formally to the hospital about my treatment, their response was defensive and legalistic. No mechanism seemed to exist for constructive outcomes. Whilst my overriding motivation was to try and prevent similar events happening to women in the future (although an apology would also have helped), theirs was to avoid litigation. Ironically, by refusing to work constructively and improve their practice, the hospital missed an opportunity to set up preventative measures which would have *reduced* the likelihood of future litigation.

#### **Guideline 5: Learn from experience**

When things go wrong, *use* the experience to improve your practice for the future.

Ultimately – and against all predictions – I registered with the first hospital. The physical access continued to fill me with trepidation, but in the end the staff there determined they would make the best of a bad job. They made room for me on the *ante*-natal ward where facilities were *slightly* better, found me a commode (which was some improvement on a bedpan), worked hard to protect my privacy and listened carefully to my explanations of what I needed.

### **Guideline 6: Assume solutions exist**

Be creative. Remember that rules can be broken and bad protocol can be got round.

In the latter stages of pregnancy, I attended two ante-natal classes – one run by the health authority, the other by the National Childbirth Trust. True to form, both involved elements of panic. I was already booked on the NCT class, access discussions already held, when they started to become anxious, suggesting I might attend another more accessible class two hours' drive away, or perhaps accept a refund. We resolved it, but it was a definite blip.

The health authority classes were held in a building where I had to take a separate, convoluted route in and sit in an allocated space until, week by week, I felt increasingly different and alienated from the women around me. Throughout, the physiotherapist would single me out for public questioning. She would talk about carrying our babies, feeding, changing nappies, putting them to bed, then turn specifically to me and ask how I would cope, what arrangements had I made. Perhaps she had guideline 3 in mind, but *when* she talked and listened, it lacked all subtlety and privacy.

### **Guideline 7: Remember your power**

As an individual, you have power to wield for good or bad. In pregnancy and childbirth, most of my highest highs and my lowest lows were defined by individuals.

At the final ante-natal class, the same physiotherapist told us about the 'reunion' planned for September. It would be held down in the lounge at the same church hall. Then she suddenly realised that 'down' meant steps, there was no ramp, could I walk, would I be carried? I wanted to shout No, *you* solve it, it's your job. Out loud, she wondered whether they could move to another room, except that the lounge was so much more comfortable, until it felt as though I would be responsible for everyone else's hardship.

### **Guideline 8: Take responsibility**

The situation is your responsibility and the struggle will be much simpler for you.

There *were* times when I was not battling alone. My lead midwife began to fight my corner with the hospitals. As she put it, she was quite taken by the challenge, but it left a bitter taste. Her involvement was crucial. I *had* to fight what was happening because the arrangements were vital to my well-being and that of my baby. But, at the same time, I worried about clashing with the very people whose job it would soon be to support me through labour.

Back in the early stages of pregnancy, the subject of screening was raised at every ante-natal appointment, although it was stated clearly on my notes that I did not want any testing. As a disabled woman, I have thought harder than most about impairment and its realities. Screening is a judgement on me and my friends and all the people who never made it and every time testing was raised I felt a visceral reaction.

To explore the very complex subject of screening is beyond the scope of this paper<sup>2</sup>, but regardless of your opinions on the merits and demerits, the *fact* is that maternity services, like the rest of society, are founded on a basic fear of impairment. When tests are carried out and people are supported in deciding on a course of action, or inaction, nothing in that process is neutral - the very language is steeped in bias: 'abnormalities', 'anomalies', 'defects' – every aspect is culturally constructed.

### **Guideline 9: Question your ideas**

Do not assume that your ideas are neutral or shared by every woman.

As I reached the eleventh hour of pregnancy, there was another panic. The health authority's manual handling department got wind that there was a disabled woman hoping for a water birth and based at home. Suddenly they were demanding that a hoist be erected on site. I was not asked about my impairment, whether I might have difficulty getting in or out of the pool, or whether there might be risks associated with my impairment. The department was not prepared to listen or negotiate.<sup>3</sup> Although the midwives were not keen on using a hoist, to avoid possible legal repercussions, I gave in. Subsequently, the midwife called to confirm arrangements: Did I know where to hire two hoists? There would be one required in my home and a second at the hospital in case of emergency transfer. Oh, and by the way, the invoice would be sent direct to me.

In the event, the layers of bureaucracy delayed things to a point where I was crouched on the kitchen floor, mid-contraction, when they finally phoned up ready to deliver it. I could not speak at the time, but when my birth partner told them it was inappropriate, it was officially recorded in my notes that I had refused the hoist. Later, after a hospital transfer, I found the second hoist waiting for me, hanging like a gallows over the bed in the tiny post-natal room. The staff spent the next four days cursing as they fell over it.

The last few weeks of labour were run through with panic – a stream of phone calls from midwives, hospitals, health visitors, social workers, manual handling – an excess of professionals. Just as all the other women went on maternity leave, my work began. Just as I most needed to rest and build up my energy for labour and motherhood, I was expected to problem-solve, make phone calls, even attend meetings. As other women turned their attention to birth, I was focused on battles.

### **Guideline 10: Think ahead**

Plan early and with maximum flexibility.

One place where early planning did happen, was in considering my potential access needs as a *parent*. Plans were made during my pregnancy for the fact that my personal assistance needs would change once the baby was born. The plans were purposely provisional, because I could not be certain of my needs at that stage, and it gave me a small confidence to know that they were in place, ready.

But back to the hoist for a moment. It transpired that it was really nothing to do with me or concerns about my impairment. When the woman from manual handling asked me what if I had a heart attack mid-labour, not a known characteristic of my impairment (but thanks for the cheerful suggestion), it became clear that I was being used to push through a generic policy for all midwifery practice in the area.

This is a classic situation. Other women had had water births, some at home, and the question of safety had not been raised. When they heard about *me* they panicked; yet all my presence really did was expose *existing* inadequacies in the system. Their reaction made it seem as though the accommodation of disabled people was excessively complex and labour-intensive, when in fact it was generic policy that needed the attention.

**Guideline 11: Do not use disabled people to solve your policy failings**

Or at least be honest about it when you do.

No one has been brave enough to answer this for me, but during the minutes it takes to lift a labouring woman into a hoist and out of a pool, what is happening to the baby whose head is clamped between her thighs?

If that thought is not horror story enough, here is another. It did not happen to me, but it is a true and recent story, and every pregnant disabled woman labours under its threat.

Penny is a disabled mother, living in Bradford. She is a full-time employer of personal assistants. When she became pregnant, social services stepped in and announced that the turnover of personal assistants would not be in the best interests of the child-to-be and that, under the Children's Act, it would be removed into local authority 'care'. Until four days before her caesarean was due, Penny had no idea whether she would in fact have a baby.

Inhumanity aside, the council's action showed a complete lack of understanding of the role of a personal assistant or how, as disabled adults, we manage our lives. The PAs were not there to care for the child, but to assist *Penny* to be a parent. The presence of her PAs specifically allowed Penny to create consistency and security for her baby.

I tell this story because, as you plan and put maternity services into practice, you cannot know the backdrop to every woman's situation. For some disabled women, there are immense issues at stake which will influence their every perception and experience of pregnancy and birth. Good communication and the removal of preconceptions are vital to providing a good and relevant service.

I also tell this story because, in it, every one of the guidelines I have raised was ignored, so that the authorities involved never did grasp the reality of this woman's situation. They did not start from a point of inclusive practice, of finding solutions, they did not listen and certainly did not recognise Penny's expertise.

Penny's tale is not just a question of can I keep my baby, but an example of how official services can create profound vulnerability, dependency and trauma. That service agency, like every other, chose the route it took.

As you continue your work in maternity services and in the lives of the individuals who use them, you too choose what route to take. You can opt for a route that causes vulnerability, dependency and trauma, that turns every pregnant disabled woman into a problem or a phenomenon. But, equally, you can choose to work in a way that supports those same women simply to be pregnant.

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<sup>i</sup> Since December 1996, the DDA has made it unlawful for providers of goods, services and facilities to discriminate against members of the public on grounds of disability. From January 2004, it will be unlawful for providers to fail to make reasonable adjustments to overcome physical barriers to access.

<sup>2</sup> For an excellent discussion of the implications of prenatal testing for disabled people, see Bailey R. (1996) *Prenatal Testing and the Prevention of Impairment*. J Morris (Ed) *Encounters with Strangers*. Women's Press: 143-167.

<sup>3</sup> Ironically, I have since met a disabled woman who *needed* a hoist during her labour but was told the health authority did not have any – such is the arbitrariness of discrimination.

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## **Guidelines for inclusion**

1. Relax. Don't feel threatened – diversity is a good thing.
2. *Decide* to become inclusive – make it your starting point and an absolute requirement.
3. Remember that the impact of maternity services on an individual is affected by their experiences and circumstances.
4. Talk and listen. Recognise people's experience and expertise.
5. Assume solutions exist. Be creative. Remember that rules can be broken and bad protocol can be got round.
6. When things go wrong, *use* the experience to improve your practice for the future.
7. Remember, as an individual, you are powerful – for good or bad.
8. Take responsibility – it *is your* responsibility and the struggle will be much simpler for you.
9. Question your ideas. Don't assume they are neutral or shared by every woman.
10. Think ahead. Plan early and with maximum flexibility.
11. Don't use disabled people to solve your policy failings – or at least be honest about it when you do.
- And, lastly 12. Don't just think about inclusion – make it happen.