Parenting and Disability
Paulines Story – Access (mp3 transcript)

I would like to talk to you about access issues for a person who has a disability.

Access can be an issue for me, although now more modern buildings have addressed the issue with ramps, it is much easier to get into some buildings now than say 12 years ago when my child was small.

However, now there are signs saying there is a disability policy and we are disability aware but the reality of saying you have a policy and using that policy are 2 totally different things.

For example, with my hearing impairment I welcome a sign that says there is a LOOP system in place. I say

"Great - today I can be an adult and speak for myself. I switch it to T BAR system - you know the hearing aid works as it worked at home earlier but if you cannot set it to T BAR then it will not work. There is a buzzing sound which interferes with something else.

Staff say to me

"Have you switched it on?"

"Yes it’s switched on"

They say "Why can't you hear me then?"

This happens in lots of places, all across the board it is the same. If there is a LOOP system in place then the deaf person or person hard of hearing can speak for themselves. If the system is not switched on or set up properly, or if people have not had any training in its use, as I do not know how the technology works, then it is no use me having it. People do not understand the system - my husband can hear me watching telly but he is not hearing what I am hearing as it is a conductive system.

I know from family members that have had babies - they say they have not been able to communicate their needs to the midwives and doctors as there is nothing in place at all within the hospital. My elder sister said how scary it was that things were being said about her and her health. She was carrying a baby with a disability but
everyone was talking constantly to her husband. Now can you imagine that you are unable to hear and you are watching all the expressions – also she was unable to lip read. You wonder what is wrong with the baby as everyone looks anxious but you have to wait until the end of the conversation to have it explained what was being said about your baby. It is as if we are a problem. Within the hospital this is a major issue but everyone should be able to speak to a doctor privately.

Another example is that my GP advertises a telephone consultation service. If I need an appointment I can ask husband to ring up but I have now said to myself do I want this?

Do I want my husband to discuss my gynaecology problems with my GP?

Do I want him next to me whilst discussing this or use my child to speak for me?

If you can imagine I can hear nothing at all and if I turn away you cannot see me and need to be head to head to lip read otherwise I cannot make out what you are saying so just say can you come in with me (name) and help me out? it would be difficult to say it but I want to say

"Can I see an English speaking doctor? " but know that is seen as not right thing to say but its not about your colour or ethnicity - I need to be able to read your lips. if I were to request this that would be a real no no. I have not got that facility like I can request an interpreter as know it costs a lot of money.

An interpreter is a way round this in that I need someone in the room to interpret for me - otherwise a pressure on the family to always be there and added pressure on child if he needs to be there.

It's a question of privacy and dignity - you may not want your child or some stranger who is an interpreter to know .should be cut down to doctor and patient.

If you lip read it is difficult to get this point across but it’s no point me being seen by someone who does not speak good English or even someone with a moustache or a beard. I have to be able to see lips as full lips equals full picture. So sometimes I have struggled to find a good doctor for me - have had to wait a long time - even struggled with a Scottish doctor.
Without the hearing aid I am completely deaf so I say to people

"I am deaf because if I remove the equipment I cannot hear you as it is only good for as long as the batteries last"

I can ignore people when I want to.

I did not start to admit that I had a hearing loss - maybe only 6 years ago and then had to get a hearing aid.

I want to make an appointment but the receptionist says she needs certain information to be able to make an appointment with the right doctor. I can see that they do not want to have time wasted but as an adult why do they presume I don't know which doctor I need for what is wrong with me.

I think they need to respect me in that way.

Staff in general do not think - it is just easier to talk to my husband but it makes me anxious when you are waiting for information. All of this has not changed much as I remember as a child the doctors would always automatically talk to my Mum so I suppose I am used to this approach.

Access is being addressed and we have met some amazing doctors and nurses but they do not have the time. When I go to hospital I walk into a room stressed and unwell. When I was pregnant I was very lucky to have a consultant who saw me as high risk so I was under his care. When he was not there I saw his Registrar instead. These appointments could be quite difficult as they would always talk to my husband and I was getting stressed as I wanted to know what was wrong with my body!

Other examples of poor communication which affects access for me are in departments such as the X ray department. They sit you in one department and it feels like 10 miles away to have the X ray done and there are no wheelchairs available although now they have little carts to take you from point A to point B. But then you have to wait around for them whereas if I had my wheelchair I could get around quicker.
One local hospital has very good access - pretty clued up with lifts etc...The GP surgery though is just bizarre and walk in centres even worse.

For example some doors are automatic and others not- ramp in to surgery but then stairs to see doctor on next floor!

When I am in a wheelchair and can’t get in some where it is frustrating but my disability affects people differently. The Genetic counsellor says there is a stereotype of what we expect people like me to be like. I have to fit a criteria.

I have gone into a room and a doctor has said you are not typical of someone with this condition either as I am not very tall and not like in the textbooks. I come from a family of 9 so I am typical of my family!

Short stature is also an access issue for me. Such as couches ......the doctors and midwives do not help you on to those couches. I think to myself "how am I going to get onto that couch so I have to bring someone in with me to help especially when I was heavily pregnant. I usually have to jump that last little bit between stool and the bed. Some couches have what we describe as "caravan steps" - not exactly ideal for someone with my disability.

Or they will leave you in a wheelchair at X ray and say

"Can you get out of the chair yourself love?"

BUT then you realise they have not put the brakes on! It seems that all this stuff came out about staff safeguarding themselves but then that has made life more difficult for me and others.

We have heard stories from friends who saythey just needed help to get in and out of the bath but now have to have 2 people to do this so some friends have said ok don’t then , leave it and feel more at risk with 2/3 people in a small bathroom and more vulnerable as where do you put 3 people in some bathrooms . The issue of care packages is that people are resisting them as do not want 2/3 people involved in tasks. Some have not accessed this help and are relying even more on their family.

I like people to send me typed minutes and transcripts of meetings. Lip reading is hard and there is an assumption that all deaf people can sign. I want to learn and it is something I feel I need in the future. I want my child to learn in case his hearing
Another problem with signing is when you can speak - I cannot hear my own voice but I understand from my family I have a normal voice and if I sign lots then I may stop speaking and my voice may deteriorate and so if I sign more because other deaf people sign then speech may be affected so maybe should only use it for meetings or appointments and not abuse it by using it all the time at home etc....as I do fear losing my speech. Lip reading was how my family communicated - my dad was deaf and he never heard any of his children speak.

One thing I have not yet touched on is when you need a signer - but none of our family sign - only use what we all use in the street surgeries and hospitals then presume if you do not sign then you are not deaf. I do understand why people think that. Lip reading is very hard and I do miss things - I miss the beginning and end of things and fill in the blanks and then Hope I got it right. It's very tiring. If I have any meetings on one day I will be very tired the next and I can feel sick and ill as I also have a balance problem as it affects bones in my ear.

What I really want is someone to ask me ‘what are your needs?’

I wanted to be asked rather than someone going to help you.

If we are asked we will tell you rather than have no help at all.