Parenting and Disability
Father of twins and a wheelchair user (Podcast Script)

Being around my children can be difficult at times because I get worn out particularly when I am in pain. I want to spend time with my kids and be a good parent and be involved taking an equal share of parenting but in reality it can at times be just too much for me.

I don’t remember any access issues before the twins were born. Before the twins were born we needed to call an ambulance to go into hospital but the ambulance service said I could go in the ambulance but they said I could not take my wheelchair. So there was me arriving at the hospital with the my half but I was effectively now immobilised. I had to borrow a not very helpful wheelchair from the hospital which meant that the rest of the time I was at the hospital until the babies were born I was struggling with a wheelchair that was not helpful and unfamiliar to me. I am used to pushing myself around, I make as much use of the arm supports as possible - this wheelchair was designed for someone else to push me around but of course there was no one else to push me around.

After the babies were born and we were sorting ourselves out to go home I overheard some of the staff chatting and it became clear that they were having a moan about me and how I had got in the way. It really hurt - after what had been a very long period without sleep. We had heard that the babies were doing fine so when we came out pleased with that good news then to hear people moaning about me getting in THE way with my wheelchair well was very upset..

I had no problem at all with access to the maternity unit. However, before the doctor moved the health centre it was a problem – taking the children when they were small to the surgery was at times a bit of a struggle but that has improved because the doctor has moved to a more suitable health.

There was an expectation that the other half would do most of the caring but I wanted to be involved and hands on and I was actually very proud that it was me who taught her how to change nappies not the other way around! The attitude seemed to be well why can’t she can just do it - some of that is attitudes to disability.
but some is also gender roles and the 2 coming together here just reinforces that stereotyping.

At one point I did make contact with a disabled parenting group but I sort of got the impression that they did not want to know me because I was a dad. It was not explicit that the group was thinking this is for mums but more that you are not staying at home all day - you are going back to work. I do not know how we would have coped if the work situation had been the other way around. We discussed that I would continue to work and my wife would give up.

One stunning attitude from a member of the general public was when I was going down the road with the kids and someone came up to me and started to suggest that they thought I was abducting the kids or something like. The thought never entered their head that I could be the parent and I had to get the kids to say "he's my dad" before this person backed off. I could only think that they thought he can't be their dad unless it was because I was disabled as I doubt they would challenge every father walking down the road with their kids.

Also sometimes have had some patronising attitudes in shops for example- but this is because I am disabled as opposed to being a disabled parent.

Q was it harder or easier then as they got older?

A for me it was a real issue until they were able to walk for themselves as until they were able to walk it was a real issue being able to take them out on my own. The trailer/buggy did work but not a very suitable way attaching this to the wheelchair- it was safe but it grated upon the ground. It was incredibly hard work. Seemed like there was no facility at all for a wheelchair using parent and no equivalent to a pushchair at all. Maybe there was something out there but never given a chance to know what was out there. The bike /trailer was incredibly expensive. No health professional suggested anything and you were expected to find it out for yourself and meet the additional costs.however as they get older doing anything with them got easier.

Wish list

Someone should automatically realise that if you have a disability and newborns (in my case 2 newborns) you do need extra help. I have never had a social worker always felt don't need one- until we had babies then yes I do think I did need one then but I was caught up in the frenzy of having 2 new babies. The combination of
being disabled and having two newborn twins was stunningly difficult; it did feel like being told you’ll have to get on with it. Told that there may be help - perhaps try this or maybe try there but basically we got some help from one charity or another. At one stage we tried to get help from a trainee nursery nurse - that was pretty useless. Her levels of skill were so minimal- everything she did had to be redone. Feeling was given from people when they were suggesting things that such a person would be a help and they would be the solution! However the reality was it took a lot of time and effort organising but was not as much help as supposed to be.

One aspect readily comes to mind was from work. I tried to get parental leave but that just did not work. I applied for it and was granted it but felt i was stil expected to do as much as full time. I decided to take one day a week instead of one big block of leave but i was expected to take work home and still do as much work as ever. That bit certainly did not work!

I had decided with my disability that i would not have kids but then you get into a relationship with someone who does want children - I sort of knew it was going to be really difficult. Even though I knew it would be difficult I was not prepared for how really difficult it was going to be especially in first few years. Especially as no one plans to have twins - just got my head around having a singleton pregnancy then we discovered we were having twins!

We had a private scan as we were worried re Down's syndrome so we had an early scan. It did go through my mind that it may be twins- but I don't think it went through the other half’s mind at all.

We live in quite a large house which we bought so that we could live wholly on the ground floor. Of course with children then issues re - getting up and down the stairs - a real issue and lack of help with that. There was the assumption that my other half would do all the running up and down stairs - but when you are talking about twin newborns this is a bit rich to suggest that she could do everything so real issues here and a real lack of understanding. One thing that is frustrating is that with Disability Living Allowance gives you a reduction in council tax of 1/9th but we need to live in a house 60 - 70% bigger than another family because I am disabled. There are a whole lot of issues re housing for disabled people and how we cope getting around the house. I have put in extra handrails in to get upstairs and I need extra heating. If I spend thousands on installing a stair lift it will immediately reduce the value of the property. There would still be that delay in answering a baby alarm so my partner would still have taken on most of the caring role and as we live in a large...
Victorian house: a stair lift will not reach the top of the landing. If I get up the stairs in a stair lift I have not then got my wheelchair to access rooms upstairs so I am stranded! I am glad we did not have to move but there is a real issue re lack of good housing available for disabled people generally but even more so for a disabled parent.

We did make a choice to have kids but we never planned to have twins!