



Community Social Care

Disabled Women and Motherhood

V/o:

Tom Shakespeare makes it clear that the contribution disabled people make to our communities and their potential to be an important part of those communities needs to be fully appreciated. For many of these individuals becoming a parent is essential in order to be fulfilled and be part of the wider community. You'll now hear the testimonies of two women with different disabilities who will talk about the challenges and the joy that motherhood has brought them. First Mary, who has a physical impairment.

Mary:

As my days start like most mothers trying to drag myself out of bed and get ready, and then get the children ready and get them off to school, and instil in them that they can't play for half an hour and still get to school on time. I think I think of myself as somebody who's never fitted any comfortable pigeonholes really because I'm an older, single parent who's disabled and I have twins, and I've never met anybody else who quite fits into all of those categories.

I really think that hardly a day goes by without disablement issues hitting me, whether it's anxiety about, you know, my helpers coming, whether it's anxiety about the Government deciding to cut benefits which may affect me, you know, whether it's other people's attitudes, whether it's questions people ask me, whether it's struggling to get some new development that would make life better for disabled people under way, and facing all the usual hurdles of disablism.

I think that when I did become pregnant I was so overcome with joy about it that I wasn't prepared to see it as problematic. I was extraordinarily lucky. I don't remember a single negative reaction to my being pregnant, neither from family or friends, and nor from the professionals, and it's the professionals bit which is I know really unusual but I just, it wasn't altogether luck, it wasn't altogether luck because when I moved to the area I was in I happened to have encountered a GP somewhere else who was very, very left wing, very radical, and so when I moved there I did decide to go to his practice, but where I was lucky was that he wasn't the only one in his practice who was radical, they all were. In retrospect their version of being positive towards a disabled person was rather much to treat me like any other mother, or any other mother-to-be, and so actually they weren't addressing needs with me that it would have been wise to address, I think particularly in relation to when I was actually delivering and also when I would be on the maternity unit, and the fact that those things hadn't been addressed caused an awful lot of trouble really.

It's very, very difficult, I think, that people who provide help, and the general public, have no idea how much hard work it entails to receive help, particularly to receive help in your own home, so looking at the obvious thing of, you know, having to show every new person where you keep all your cleaning things, and what it is you want done and all the rest of it, but you've also got to adjust to each individual person's personalities, and somehow you've got to accommodate their personality, their way of doing things, and their needs, and still carry on your life as you, you know. So I think it's enormously demanding to have help in your home.

I'm acutely aware of how lucky I am to be somewhere where given that, you know, I'm not living in an extended family and given that community has broken down to a large extent, there is nevertheless a statutory provision to support me, I'm aware that that has been crucial, and for all that I might criticise the systems, which I do regularly, I'm also aware of my indebtedness to having that system there, how important it is.

If I was asked what central piece of advice would you ever give to another disabled person contemplating parenthood, I would say make very sure that you get yourself a good advocate,

because I know I can't advocate for myself half as well as I can advocate for anyone else, and everyone I know says the same thing, and if I hadn't had an extremely good advocate with me, actually in the hospital when I was trying to get my care package set up, I think it would have been a major disaster, partly because she was already a parent and she knew what parenting meant and partly because, you know, just after the birth of your children your brain is like cotton wool and you can't think it through properly for yourself.

I am afraid of increasing impairment but not so much the impairment as the pain actually. The impairment itself isn't quite such an issue 'cos like I say I know all sorts of coping strategies, but I am afraid of the impact of increasing pain, particularly on my capacity to earn my own living. So I'm not inclined to think the future's going to be easy anyway, I'm inclined to think the future's, it's going to be harder in many ways, but to imagine a future with my own children in it is a source of constant wonder to me, I mean I on a daily basis I have these kind of feelings, overwhelming feelings of wonder that these two wonderful, gorgeous, beautiful, thrilling, exciting children are my children, and I think that will always stay with me...

V/o:

Now listen to Kate. She has experienced mental health problems in the past.

Kate:

I always wanted to be a mother. I thought it would be a wonderful experience and that has been confirmed to me by having a daughter.

Well as a child I always had very strong maternal feelings. I liked playing with dolls, I had two younger sisters who I liked mothering, I've always liked children and I've always wanted children, and I think when I developed a mental health problem I just couldn't see any way that I could possibly cope with children, or that in fact anyone would want to marry me because I had all these awful labels, so I'd given it up really, I mean I didn't even know if I was going to live, let alone have children.

Like most people who have a long-term mental health problem I've been given a number of diagnoses or labels, and I was described at one point as a well-know chronic schizophrenic which is a pretty awful label to be given, so I've been told I have schizophrenia, I've been told I have schizo-affective disorder which seems to be schizophrenia and depression, I've also been told I've had a psychosis, a depressive illness, an anxiety state, sort of a mixture of all of them really. My husband knows what it's like to be on the receiving end, I mean we've had our ups and downs but he's been very, very supportive. We actually met in the inpatient psychiatric unit so we've seen each other at our worst. Probably like most first-time parents we were quite anxious about our ability to cope but we both wanted a child very much, I mean we didn't meet with some very negative attitudes when we were considering having a child and so when I was pregnant, and also when our daughter was first born, but I think the strength of our relationship, you know, helped us through that. I mean my family, my parents and sisters, certainly when I was at my most ill, I mean they really didn't know what to think, they really wanted me to be in hospital because then they didn't really have to worry about me so there was some conflict there, although that has been resolved now, and also when I was thinking of having a child they were very concerned, they didn't think I would cope. But I think it was more out of concern and worry rather than anything else.

I'm actually expecting our second child in a few months which I'm very much looking forward to. I'll certainly have less qualms than the first time because obviously I wasn't sure on our ability to cope but we're very much looking forward to it.

One of the things that really added to our anxiety about our ability to cope was the attitude of a consultant psychiatrist. I was seeing him for the first time as we'd moved to a different area, and I was asking advice on taking medication during pregnancy, and his response to that was that we actually shouldn't have children, you know, we'd be passing on defective genes and he also said if I became ill the child would be taken away, no doubt about it. I mean this obviously freaked me out quite a lot, you know, it's an anxious time anyway so it made me feel, well it made me feel quite angry actually but also very, very anxious. My GP was very supportive. Even though I'd moved I was lucky to be able to keep the same GP. He'd also

got to know my husband a bit as well and had seen us together, so he was very supportive, yeah.

I think like most mothers I feel tired more often than I used to, that's normal. I mean just after my daughter was born I did actually develop post-natal depression and it was a different sort of depression or illness to that that I'd previously suffered, and it actually went, because of that it actually went unrecognised for about nine or ten months so I was actually post-natally depressed, but because of my previous experiences they hadn't taken it seriously.

I think she is aware, I mean I don't think she has a concept of mental illness or mental health problems as such, I mean she knows that I'm sometimes unwell, that I get stressed, that I sometimes need time out, she's very aware of that. I mean I think in time her awareness will grow but she seems very sensitive to how I'm feeling, I mean she was just three years old when she came up to me and said, how are you feeling today, Mummy, you know which was quite, you know it was lovely to hear actually. I think it's actually helped me achieve more because I've got much more confidence in my abilities to cope, you know having to think of another person the whole time it takes the focus off yourself, which I think has been a good thing. I mean there've been times when I've overstepped the mark and been totally stressed out but that's, in a way, allowed me to know what my limitations were which, again, is you know a good thing.

We now feel more of a normal family. When we're out and about people see us as a family with a child. People see the child first and the family, we feel much more part of society, much more integrated, much more accepted.

V/o:

There are organisations to support parents like Kate and Mary, and to ensure they get good information when they need it. The Disability, Pregnancy and Parenthood International Journal is a non-profit making publication which aims at promoting better awareness and support for disabled people in pregnancy and parenthood. It also runs an information service. Through both these activities it's been able to find out what issues really matter to its readership, which includes health and social work professionals, and disability organisations. The organisation has no rigid criteria for the kind of individual it can assist as Information Officer Becki Josiah explains.

Becki Josiah:

Well we wouldn't define the category of people we could help, they could define themselves if they have a need and a long-term health problem or condition they can call us and ask us for our information, and that would include people with mental health difficulties, learning disabilities, back problems, wheelchair users, or somebody with diabetes may ask us for information.

V/o:

Lisa Nicholls, also an Information Officer, has been with the DPPI from its inception. Here she comments on the kind of service it provides and its role.

Lisa Nicholls:

Very often the calls are urgent. I think that the most urgent ones are quite often to do with child custody and children being put on 'at risk' registers or being threatened with removal from families because there is some sort of familial disability, and there may be a case conference happening tomorrow and people need very urgent and desperate input in terms of their rights. A lot of the inquiries include some aspect of there being a practical difficulty, or the need to look for particular types of equipment, but that's usually combined with other issues. Needing information about perhaps their own specific impairment or condition, and the effect of pregnancy, or what they can expect, what they need to plan for. Other support groups out there that they can get in touch with, other disabled parents, because I think one of the issues is that disabled parents quite often feel very isolated and very much that they are the only person who's experiencing the same feelings or issues, and to put people in touch with other parents is quite a powerful tool. There are lots of disabled parents who are actually there for their children because maybe they're not working, for example, so they're

there all the time. Certainly we've heard of many disabled dads who have said, you know, I spend a lot more time with my children than most dads do, and that's a really good thing to bring out. I think they're very motivated; many disabled parents are very motivated and very keen to be very positive parents.