



Community Social Care

Disability and Difference

V/o:

Disability and difference. Later on you'll get the opportunity to hear the experiences of disabled parents, and of one particular organisation which exists to support them. You will also hear extracts taken from a discussion on the possible implications of genetic research and abortion for disabled people. First, listen to this song called '*Disability Blues*' by a band called *The Fugitives*, and published by Tyneside Disability Arts. It originates from the Disability Arts Movement and challenges the system of care which many disabled people experience.

SONG:

Yes I'm feeling frustration
I've got nothing better to do
Yes I'm feeling frustration
And my request has been refused
I've got no transportation
I've got the disability blues
Yes I'm feeling quite nervous
And my nerves are about to snap
And when you finally get service
And it's absolutely crap
You know I didn't deserve it
I'm in the disability trap
Oh yeah!

V/o:

The song you have just heard explores the lack of control that many disabled people experience over their own lives. Now you'll listen to extracts taken from a 1998 BBC Radio 4 programme called '*A Life Worth Living*' which explores the impact of continued research into genetic screening and therapies on the lives of disabled people. It's another area where they can feel left out of decisions which can affect them. Those at the forefront of the debate, both geneticists and people with disabilities, took part. One of the contributors was John Burn, Professor of Clinical Genetics at Newcastle University. He was instrumental in setting up the Centre for Life which aims to improve the public perception of genetics. Here he explains why he believes in the power of genetics to improve our lives.

Prof. John Burn:

Some people say that pre-natal diagnosis devalues people with disabilities. Most people I meet don't connect the two. We cherish those we love, yet we can go to great lengths to ensure a future child does not have the same disability. I was part of the team which showed that all women should take extra folic acid when they plan to get pregnant because this simple, safe vitamin could reduce the incidence of Spina Bifida by over seventy percent. To suggest that doing that research meant I thought less of the people I know with Spina Bifida is silly. Does pressing for children to wear crash helmets on their bikes mean I don't value those children already paralysed in accidents. Genetic advances will open the way to couples checking for such gene faults before starting a family. We'll need to decide as a society where to draw the line. Should we offer to end the life of a foetus who'll be deaf, or severely short-sighted? These are difficult issues but amenable to rational discussion.

V/o:

Professor of Genetics at University College, London, Steve Jones, also took part in the debate. He aims to unravel the moral maze presented by Professor Burn and, as you will hear, feels there are two parts to the debate that can be confused.

Prof. Steve Jones:

I think there are two rather different issues, one of which is the nature of genetic research – whether you should spend money on it, whether if people's hopes, or indeed their fears, are exaggerated, and I think both of them are, and I think that's an interesting debate. And there is I think a rather separate debate about society's attitude towards disability, and they don't really overlap all that much, I mean once you accept, as we do and I think there are strong, powerful moral issues involved, once you accept that women have the right to choose to terminate pregnancies for which may be perfectly healthy on the grounds that they do not wish to have a baby, then it seems to me you really have made the major acceptance, and it's rather difficult then to fractionate people's decision on the basis of the quality of the child they may or may not have. So I think really once you've accepted that there's an element of 'the swallow and the camel and the swinging of the gnat' here, and part of the problem of course in the larger sense is that if you were to have this debate in the United States, this argument about the rights of disabled people would become immediately entangled with the anti-abortion movement, and I think one has to be rather careful not to mix the two things together because they're really quite separate.

V/o:

Now listen to the arguments put forward by Sian Vasey who has a condition, Spinal Muscular Atrophy. She wants to challenge the way she's perceived and feels that money spent on genetic research preventing the impairments of the future could be better spent improving the lives of disabled people today.

Sian Vasey:

My voice, if you like, is the voice of the disabled person who just wants to be legitimised as a disabled person. There are plenty of us who don't wake up in the mornings thinking, hell, I've got Spinal Muscular Atrophy, God, this is terrible, I'm blind, this is awful, we just don't do that. I don't have a sense of myself as a tragedy and I'm not particularly at odds with my body, and I would like to be able to live my life and I know a lot of other disabled people come from this school of thought without being constantly cast in the mould of somebody who is actually in need of cure. I think you can't argue with the notion of choice and a woman's right to choose. Unfortunately though I do think there is such a profound level of ignorance about the reality of what it is to be a disabled person, and I really do mean profound.

V/o:

Taking part in the programme alongside Sian was Margaret Jones, who also has the condition Spinal Muscular Atrophy. She's keen to point out that not all disabled people share the same experiences or opinions on those issues.

Margaret Jones:

I'm very happy the way research is going. On a very basic level I'm quite happy to be me. I have a very good life and like Sian I don't wake up every morning thinking, oh dear me, this is a tragedy. I really enjoy myself and I have a good life, but I also think I would have a good life if I was able-bodied as well. I think that disability in a way is irrelevant to that. But people like Tom Shakespeare who were talking about they'd rather be as they are, and they don't need a cure, I think don't speak for the people who have a deteriorating condition. Some of us don't have a choice to stay as we are. For some of the neuro-muscular conditions, particularly some of the forms of Muscular Dystrophy and the Type I of Spinal Muscular Atrophy, the people that inherit these conditions are born to die. There's a total, irrefutable deterioration in the muscle strength and it inevitably leads to death.

V/o:

And finally here's Dr. Tom Shakespeare. He's inherited Achondroplasia and the condition has also been passed on to his daughter. He's been keen to express the urgency of his

concern at the direction and progress of genetic research, and also works at the Centre for Life in Newcastle.

Dr. Tom Shakespeare:

I think that there's a lot of ignorance about what it's like to be a disabled person. There are some very, very significant impairments out there but lots of impairments, and deafness is one of them, Achondroplasia is another, aren't serious, yet the public perception is that to be disabled in any way is to be inevitably invalid invalid (sic), and I think we've got to challenge that. I think that it's very clear that we're not arguing with the reproductive decisions of individual men and women. What we're arguing is that the society, the NHS, the system which these decisions take place in should be supportive to people continuing with pregnancy having disabled children, if they feel able to do so, that's what we want, a real choice. I've tried to say that all impairments are different and what part of listening to disabled people is listening to different people with different impairments. Now I'm quite prepared to accept that there are some very much more significant impairments and screening might be very appropriate. For example, something like Tay-sachs disease or Dushen, children die very young in a very unpleasant way; I would advocate if a parent wanted a pregnancy for that condition, I would have no problem with it whatsoever and I think the problem is if we lump it all together. My argument is with a society which lumps it all together and thinks that disability is inevitably tragic. If we take drastic situations it's easy to know what to do, but what if we take things like late-onset conditions, things like breast cancer, things like colon cancer – do we really want to have a state of tentative pregnancy where we're going to test pregnancies for all these different conditions and terminate people who might have a very good quality of life for many years and who through interventions, medical interventions, could be cured of a particular disease or condition. Huntington's is a late-onset condition. If we had terminated, if we could detect and terminate people with Huntington's chorea we'd never had Woody Guthrie. As a folk music fan I think the world would have been a worse place, and that's what I'm concerned about.