



Collection Title (Bold Arial 10pt)

A Secret History of Sterilisation

Liz Tilley (narrator)

In the early 21st century, the sterilisation of women with learning disabilities in the UK is increasingly rare. Since the 1970s, with the move from institutionalisation and the consequent rise of care in the community, the practice has been partially exposed, but to a large extent remains a hidden history.

In this programme we introduce aspects of this history through the voices of survivors - women who have been sterilised, social historians and a legal professional, in the belief that an understanding of the past will inform ongoing discussion and research that's relates to reproductive choice, disability, human variation and technology.

I am Liz Tilley, a lecturer in the Faculty of Health and Social Care at the Open University. I also chair the Social History of Learning Disability research group.

Research suggests that many survivors were involuntarily sterilised as young teenagers.

Liz Tilley

Ebba Heronsdotter is from Iceland

Ebba Heronsdotter

She was sterilised when she was 14 years old and at that time she lived with her parents and siblings. And when she went to sterilisation as a child, she was told the appendix had to be moved.

Liz Tilley

Leilani Muir is from Canada.

Lililani Muir

I was fourteen and a half the day that I went to the surgery. The nurse took me over to the clinic and I was told that I was going to have my appendix out and there were four of us who had surgery the same day.

Liz Tilley

In the western world, involuntary sterilisation was deemed legal in parts of the US, Canada, Europe and certain Nordic countries into the 1970s. In Iceland for example, sterilisation was legalised between 1938 and 1975. Formally this required the person's consent, though as we shall hear this was not taken seriously. Ebba is now 59 and recently visited the UK to attend a

learning disability conference at the Open University. We talked about her experiences in the garden, together with Gudrun Stefansdottir, who works in social pedagogy in Iceland and who acts as Ebba's translator.

Liz Tilley and

Ebba Heronsdotter

Ebba can you tell me how old were you when you found out you'd been sterilised? She didn't know about it until she was 27 years old. When she was knew. When she knew about it she was at the institution. 5 women were going to be sterilised and they were having lessons about why and how it and Ebba asked why am I not in this group? And the woman in charge told Ebba she had sterilisation when she was 14.

How do you feel about it now? In the beginning she was angry but she's accepted it but what she was angry about wasn't so much the sterilisation but that she couldn't decide by her self. She hadn't been thinking about having a child then, but worse was the fact that the decision wasn't hers.

Liz Tilley

Ebba now lives independently with her husband in Reykjavik and is one of many women who was sterilised without their knowledge or consent. As she describes, it was primarily the sense of deception that caused her the greatest anguish. 45 years later, I asked her who she holds responsible?

Ebba Heronsdotter

It's the community that decided to do these things even though it was her mothers decision, it was because how the society was at that time. So the government should do something for people who have experienced this.

Liz Tilley

And that is exactly what has happened in the landmark case of Leilani Muir, in Alberta, Canada - Leilani is the first person to file a successful law suit against the province of Alberta for wrongful sterilisation. She recalls the moment she discovered she had been sterilised.

Leilani Muir

I was babysitting and I thought well I'm gonna go to the doctor and he asked me about the scar. I told him. I was in this place. They told me they were taking my appendix out. The scar was that wide and that long - very sloppy, very sloppy. And he says, that's not an appendix scar. He said they did more than just take your appendix out, he said, you can't have children. This is the first time I had found out I was sterilised. There was only a quarter of an inch of my left tube left.

Liz Tilley

Leilani's case summary reveals a great deal about the history of sterilisation in Canada. John Faulds, of Field Law, represented Leilani at the trial.

John Faulds

The case arises out of the implementation of a eugenics law in the late 1920s. It allowed a board to order the sterilisation of persons who were brought before it and at first, when this law was passed, it was subject to the consent of the patient involved. No operation could be carried out unless that patient agreed. And you have to remember in the 1920s, in Canada and probably many other jurisdictions as well, any kind of operation to sterilise somebody, to limit their reproductive capacity, was considered to be an assault and couldn't be carried out, even with the person's consent. After a few years, the government realised it wasn't getting very much business - not many operations were being carried out because people weren't inclined to consent to that kind of procedure, and so they removed the requirement for consent in the case of persons who were deemed to be mentally defective.

Claudia Malacrida

The Eugenics system in Canada was highly routinised in similar ways to what happened in Germany and yet it was all very benign and banal.

Liz Tilley

Claudia Malacrida, talking to us via a long distance internet line, from Japan, is Associate Professor of Social History at the University of Lethbridge in Canada.

Claudia Malacrida

The Eugenics board met 4 times annually, in formal ways. One in Michener centre, one in Ponoka, which was a mental health facility, and then a couple of times in hospitals and then there were these itinerant guidance clinics that covered the outposts. These were sort of roving groups of psychiatrists, health nurses, guidance councillors, sometimes clergy and often educators who would visit small rural towns and collect a list from the local physician, or local clinician about who would be a likely subject for sterilisation.

You know a family doctor might say oh, why would you want to worry about having menstruation that's so messy and it only hurts the child and she would never be able to be a mother, so let's just take care of that.

Liz Tilley

Leilani was admitted to the Provincial Training School - the Michener Centre that Claudia mentioned, when she was 10, at the request of her mother - an alcoholic. She cannot recall

being examined for her mental capacity by psychiatric doctors and only has a vague recollection of the Eugenics board who would ultimately give the all clear for her sterilisation.

Leilani Muir

I don't remember having an IQ test or anything done there or before I went in there. But they classified me as a moron an IQ of 64 and a verbal IQ of 70. We went before a board and I only remember this as it stuck out.. they asked me, how old is a baby when it starts walking and talking and I already knew because I had a little brother so I said one. On that board I found out later that there was only 2 professionals. And on all the files it had clear, clear, clear - that was clear fro the surgery.

John Faulds

One of the psychiatrists who examined her and who gave evidence at the trial said that "It would be difficult to overestimate the degree of harm that such a series of events would cause on a young woman, particularly a young woman who is seeking to rebuild her self image and her self esteem after having been wrongfully placed in an institution for most of her young life on the grounds that she was mentally defective."

Liz Tilley

Not only would Leilani have been able to make her own decision about whether to be sterilised or not, she was wrongly held in a mental institution for 10 years of her early life. But despite the compelling evidence, John Fauld recalls that it was an extremely difficult case, given the huge implications for the Province of Alberta.

John Faulds

Leliani Muir was one of 3000 people who had been sterilised and a successful claim on her part meant the risk to the government having to deal with a large number of claims after. That said it was a difficult claim to defend. It meant defending a practice that most Albertans considered unacceptable. Secondly, the board that was supposed to implement it properly had not followed the safe guards or standards that it was required to follow and had used the law for ulterior purposes.

Liz Tilley

Decisions to sterilise were often taken regardless of the young woman or indeed her family's interests. But data that exists for the more recent past in England and Wales indicates that mothers have been key to the referral of their daughters for sterilisation. Furthermore, those who involved the courts were commended for consulting with a range of medical and legal professionals.

Alison Stansfield

Going through the courts for a sterilisation is long and arduous process and in fact those mothers who did that referral had positive comments written about them in the main and were obviously strong character who were doing what they felt was best for their daughter with learning disabilities.

Liz Tilley

Alison Stansfield is a Community Learning Disability psychiatrist..who has undertaken critical research on the recent history of sterilisation of women with learning disabilities.

Alison Stansfield

That came across quite strongly although it's very difficult to state that specifically, but certainly when I was talking to the official solicitor, family lawyers who were around, they had the same sort of feeling - that it was the mothers that drove the process.

Liz Tilley

Alison's research focuses on legal records from the 1980s and 1990s. Prior to this, we only have anecdotal evidence available, such as Pauline and Diana's story. When Diana, who's now 60 and married with a step family, was a year old she contracted measles and meningitis which resulted in brain damage. Pauline, her mother, decided to have Diana sterilised when she was in her teens. Jan Walmsley, Visiting Professor in the history of learning disabilities at the Open University, discussed Diana's sterilisation with Pauline, for this programme.

Jan Walmsley and Pauline

When you made this decision, what did you actually do? How did you approach it? Well I went through my doctor and he gave me a specialist and he thought, Diana looking normal, she was ok, but then when he interviewed her, he said, I'll do it, the operation.

Was it a difficult decision for you?

Well she always blames mother for not letting her have any babies and I said to her well you'd have about 20 by now Diana wouldn't you? And then she went missing this time and this chap had her in a room and locked her up, we had to have the police and everything and they wanted us to take it to court, but how can you have a handicap stand up, she wouldn't understand the questions or anything. SO he got away with that he'd done to her, so if she hadn't been sterilised, how many babies would she have had.

So this actually happened after she'd been sterilised? Yes, thank goodness for that. Diana couldn't cope with a baby, although she's granny to this chaps children I mean even now, how

she's got on in life, I don't think she could have coped with a baby. At least she could go out to clubs and I know she wouldn't get pregnant.

Liz Tilley

Pauline argues that having Diana sterilised gave her more freedom, but it only protected her from the consequences of sexual abuse not the abuse itself.

Today, the use of long-term contraception appears to be replacing surgical sterilisation but the question of what this means for women with learning disabilities remains. Many women are not informed and are not given the opportunity to understand the contraception they are prescribed, or to consider whether it is needed at all.

Michelle McCarthy is senior lecturer in Learning Disabilities at the Tizard Centre in the University of Kent who recently interviewed 23 women with learning disabilities to assess their level of understanding

Michelle McCarthy

For some of the women, there was a feeling that just the concerns about a woman getting pregnant were enough in herself to get her pregnant, so the fact that she wasn't having sex with men was kind of taken out of the equation - almost like it didn't matter. You had to have contraception anyway. It's what I've called the Just In Case approach. IN a lot of cases it's about if they were to be sexually abused by somebody. It was a strange attitude and not entirely clear what was behind people's thinking. That came across very strongly, both from the women themselves and from those who surrounded them, whether that's medical staff or their carers in their residential services or indeed their parents if in deed they live with their parents.

Liz Tilley

In this introduction to the sterilisation of women with learning difficulties we have highlighted some of the history and experiences, but We leave the last word to Ebba, who is concerned that women who have been sterilised share their experiences.

Ebba Heronsdotter (in translation)

She thinks its very important that women all over the world talk about it because it has been such a secret all over the world so she thinks it's very important to share the experience not only from Iceland, but from all over the world