Senate Inquiry into the Sterilisation of Women with Disabilities

Addendum Submission

Accounts Three & Four

Background:

This is the addendum submission from Women With Disabilities South Australia into the Sterilisation into women with disabilities. The original inquiry was on the 19th of February 2013. This was attended by six women (including three from the organising party WWDSA). Four women from a large institution in South Australia had indicated that they wanted to attend the Sterilisation However, due to staffing issues at the institution none of these women were able to attend. Women With Disabilities South Australia were keen to include these accounts, so we held a small discussion group on the campus of this institution.

There were eight women around this table, aside from three from WWDSA, three were staff, and only two were clients. Owing to the fact that this session was not overwhelmed with information, these accounts will be considered within one document.

It was pleasing to note that there was some information provided to the two women, in preparation for this session. With this in mind we began the session by introducing ourselves and why we made attempts to include these women in this Inquiry. We also explained that both of the women could remain anonymous if they wished – to which both indicated that they would like to take this option. As such these accounts will not include any identifying information about these women nor the institution they are connected with.

Discussion:

[R4] I live in my own home, with my two cats; I work as a cleaner here on campus. And I spend my free time on internet. It is very important for me to show that that I care for others.

[R5] I also live in community, and is still supported by the institution. Lives with one other person and I left between 1969-1977. I work the packaging section attached to the institution.

(There was then a short discussion and recognition of different experiences that we have all had in relation to sterilisation—as well as the way that they learned about these issues).

[R4] My parents were part of the Exclusive Brethren. As such I was taught nothing about getting my period. Living in this environment meant that we were not allowed to have boyfriends, had to wear long dresses I remember having to have my hair to my shoulder, and we lived without things the other young people may have had – especially girlfriends, boyfriends or anything modern not taught anything about sex. I knew nothing about sex. I eventually go hold of people and began to talk to them about sex I was 30-34.

[KA] Did you just have to deal with periods?

[R4] I just lived]with it but the started Depo-Provera at parents insistence [pending family move to Singapore, and I stopped it at aged 48, and I'm now 50.

[KA] So that's a whole world you knew nothing about. I guess you had to learn about periods once you got them or did that just happen to you?"

[R4] Yes

[SG] Did you get your period all the time?

[R4] Eventually I started, I can't remember what age. When I did, I had to live with it - until mum and dad who where going to be moving to Singapore (which never eventuated), they started me on Depo-Provera. I eventually stopped having Depo-Provera; at whatever age I did. But my period stopped at 48-I'm now 50.

[KA] So how did you talk to your doctor about that decision to stop? Did you just say to your doctor No More?

[R4] No, I just stopped because I found out that Depo-Provera makes you put weight on and this was when I stopped it a bit, and then went back on it; and that's when I spoke to my friend and the doctors and then eventually stopped it myself.

[SG] So when you were younger you didn't have a period, you just went straight on to Depo?

[R4] ERR Yeah

[Staff Member] But did you have your period a little before you went on it?

[R4] Yes, but I was a heavy bleed {sic} so that why I was put on…so yeah

[MC] If I may ask did you find that you were able to handle your period yourself?

[R4] I didn't get too moody I was still able to get about and do things for myself.

[Staff Member] So after you came off depo did your periods start again?

[R4] Nods

[Staff Member] And you managed them?

[R4] Nods

[MC] How did it make you feel to get your period? Did you feel sick or did it make you feel like a woman?

[R4] I was sorta [sic] happy, but not happy all the time. I sorta [sic] snapped a bit but other than that I wasn't too bad.

[KA] So the normal {hormonal] stuff then. I think we all know what that's like. So what about you R5? What has your experience been? Do you want to tell us?

[R5] Yes there is. I use to have the belt with pins, but because I have Cerebral Palsy I couldn't manage that, so then I went on to use the sanity pants – and I was thirteen I think when I got mine (periods), but I didn't know what they were until mum and dad or mum told me. And then when I was 45 I they got me onto the needles because my bleeding was too heavy. And I haven't had them since. I'm 57 now.

[KA] So you've probably been through menopause then?

[R5] Yes probably.

[KA] So they probably helped you go through menopause. So who had those other conversations with you…you know about sex and contraception? You said your mum told you about your period, was it your mum who also told you about sex?

[R5] Well I have two older brothers, and I was an accident and she got sick and fell pregnant but when I was born they had to turn me around, and when I came out they said "thank God she's alive", but the cord was wrapped around my neck. It was lucky that I

was alive and kicking and all that, I became a blue baby. And that's when they said I have Cerebral Palsy. I've been slow learning [sic] because my brain is not functioning properly. I did go to a 'normal' school but then I came here because I couldn't go to a normal school after grade five, I ended up coming here.

[KA] And then you lived here for a while as well?

[R5] Yes, I lived here until 1977 and then went and live in in another Institution, then I live with the Salvation Army for a while, and then I went out into the community. Apparently my sister put my name down for the nursing home over here… Whether I get in or not I don't know. I got another lass that lives with me now and she helps me out a lot.

[KA] But you're not nursing home material yet…I mean we all slow down as we get older.

[R5] Oh I've got problems with my walking, and my back hurts, and I have injuries.

[KA] Ahh so do you have your own GP, I mean doctor?

[R5] Yes.

[KA] Is it a man doctor or a lady doctor?

[R5] A lady doctor.

[KA] And how do you get along with her?

[R5] Good. It used to be a man doctor but he retired.

(Short banter about the types of thing this woman speaks to her doctor about. She has sought information about cancers and other health related issues).

[MC] Have either of you had boyfriends?

[R5] I used to have a boyfriend but he used to keep wanting to have sex, and you don't know what you might catch; Aids…I think that when you're pregnant it's hard to look after babies, because the man might give you Aids.

[KA] It sounds like you got a bit of information from somewhere. Sex can be a little bit risky but it can also be good and nice. You can have sex the mean s you don't fall pregnant and so that you don't catch disease. There is always two sides to it and so we need to

hear both sides before we make up our minds. Did you have any information about how not to get pregnant or catch diseases, from your mum or anyone else?

[R5] I don't think so.

[MC] So who told you that you could get Aids?

[R5] I heard it on the news and through other people…you know. And like smoking is bad. And they could put holes in the condoms.

[KA] Well yes its true, smoking is bad. But 99.9% of the time condoms are safe". We can get scared if we hear how bad things are, but that why we need to get all the facts about different things. But its still your choice. Does that make sense.

[SG] Can I ask R4, were you told about any side effects of the Depo?

[R4] Shakes head

[SG] So it was just given?

[R5] Nods in agreement

[SG] So you didn't have any say in the matter

[R4] Shakes head

[SG] Did you wonder what happened to your period – why it went away?

[R4] Shakes Head

[SG] It was just one of those things?

[R4] Nods in agreement

[SG] One of the things that the Senate Inquiry was looking at was informed consent.

[KA] Yes in other words was it ever explained to you in a way that you understood what it was that you were saying yes to?

[R4] My parents just organised everything without asking me.

[SG] Did the doctor ask you or say anything to you when have gave it to you?

[R4] Shakes head

[Staff member] We were talking before about the culture of the 60's, 70's and even the 80's when it wasn't which wasn't pro rights.

[KA] it was just done. and that's why there is this inquiry.

[Staff member] Is it still happen even without the guardianship board. Banter between us and staff…

(There was then short discussion about how many women in different communities have been denied the right to have children; and how this ideology can be passed on through the medical profession – from generations past to today's generation of medical professionals)

Thinking about having children, neither woman thought of having their own. R4 was pretty involved with her nephew who wanted a cuddle from her; she stated has involvement with church children as well. While R5 said she didn't know whether a child would have a disability or not; she too has nephews and nieces but not a lot to do with them.

Concluding Remarks

The session ended with an overview of what was discussed, and why it was important for as many women with disabilities to have input into the Senate Inquiry into the Sterilisation of women with disabilities. Surprise was express by the Staff in attendance that this was still an issue for women with disabilities – while at the same time acknowledging that this was also an issue for men with disabilities.

In closing the session, WWDSA urged the ***all*** the women around the table to endorse WWDA's request for a formal apology be given by the Federal Government to every woman and young girl who had been sterilisation against their will and without their informed consent.