

Not a Remotely Suitable Topic for Discussion



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

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Research Initiatives

Before 2000

Largely legal summaries/opinion pieces

Small amount of qualitative data

- Parent opinions
- Sexuality of ID people

Small convenience samples

1994-2000 -No non-medico/legal studies (Begin. 2008)

Primarily USA based databases (e.g. Spicer. 1999)

Since 2000

Diversity of research initiatives

- Case-note audits (Roy. 2010)
- Engenics impact (Ronen et al., 2009)
- Oral testimonies (Malacrida. 2006, OUP. 2010)
- Self advocacy/sterilization case study (Roets et al., 2006)
- Literature review (Begin 2008)
- 'growth attenuation' (Bersanti 2008)
- Sterilization and community views (Hamilton, in prep)

Rationale

United Nations Convention on the Rights of Persons with Disabilities - Article 6 & Article 23

Who has benefitted from recent legislation & policy changes (Hamilton. 2006, 2009)

Sterilization is as much about social customs, notions of worth, ideas about ID women's 'nature', the notion of bodily integrity as taken for granted right enjoyed by non-disabled people

The lack of men's voices in the ID and sexuality dataset– esp. the voices of white, first world, well off and well education men.

Mother Seeks Girl's Hysterectomy

<http://news.bbc.co.uk/2/hi/health/7032736.stm>

Three prompt questions

- Should the mother have the right to make this decision without the permission of her daughter?
- Do you think she has made the right choice?
- Do you share Scope's concerns or have a personal experience to share?



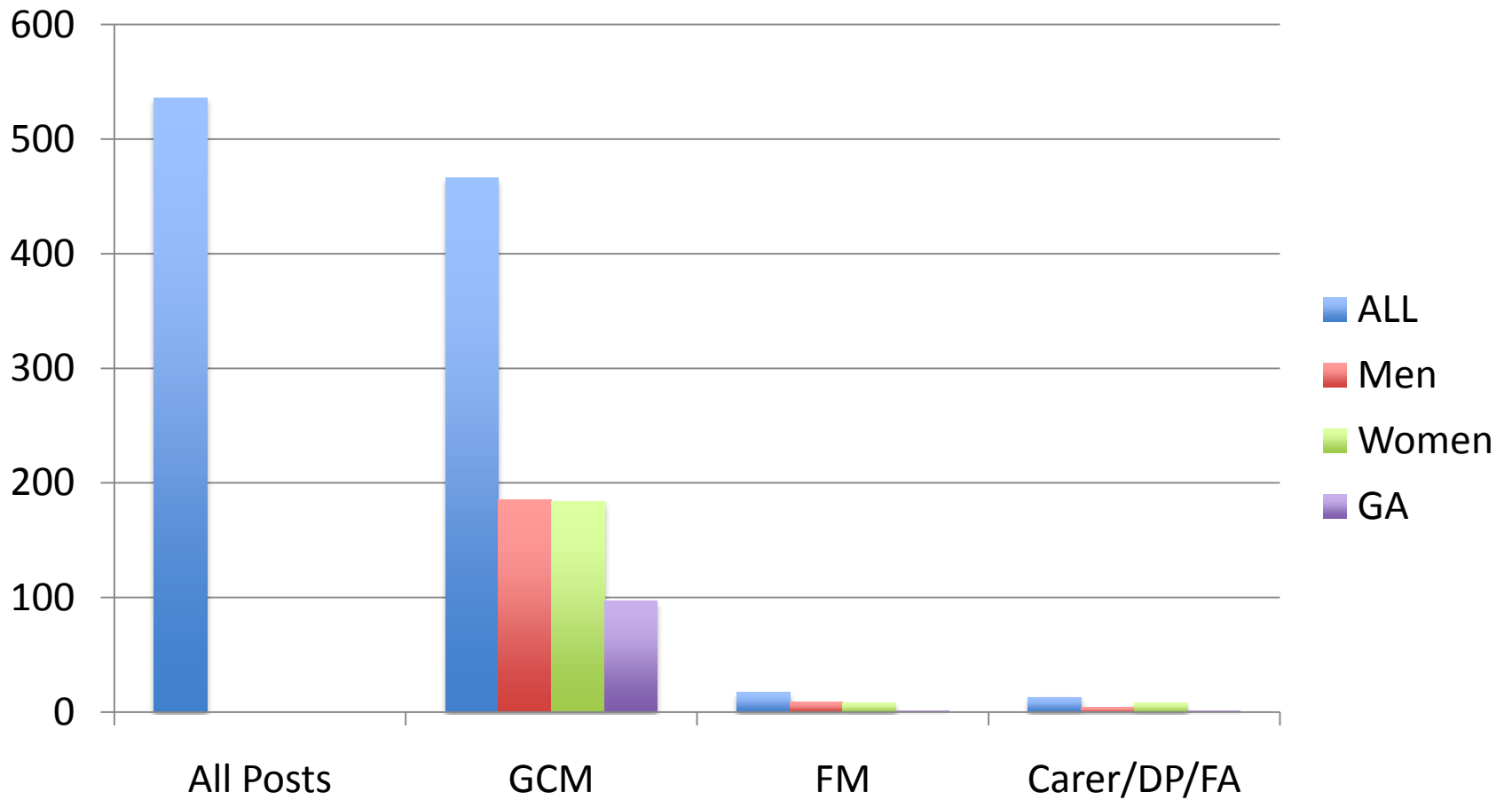
Methodology

Community Group Sample

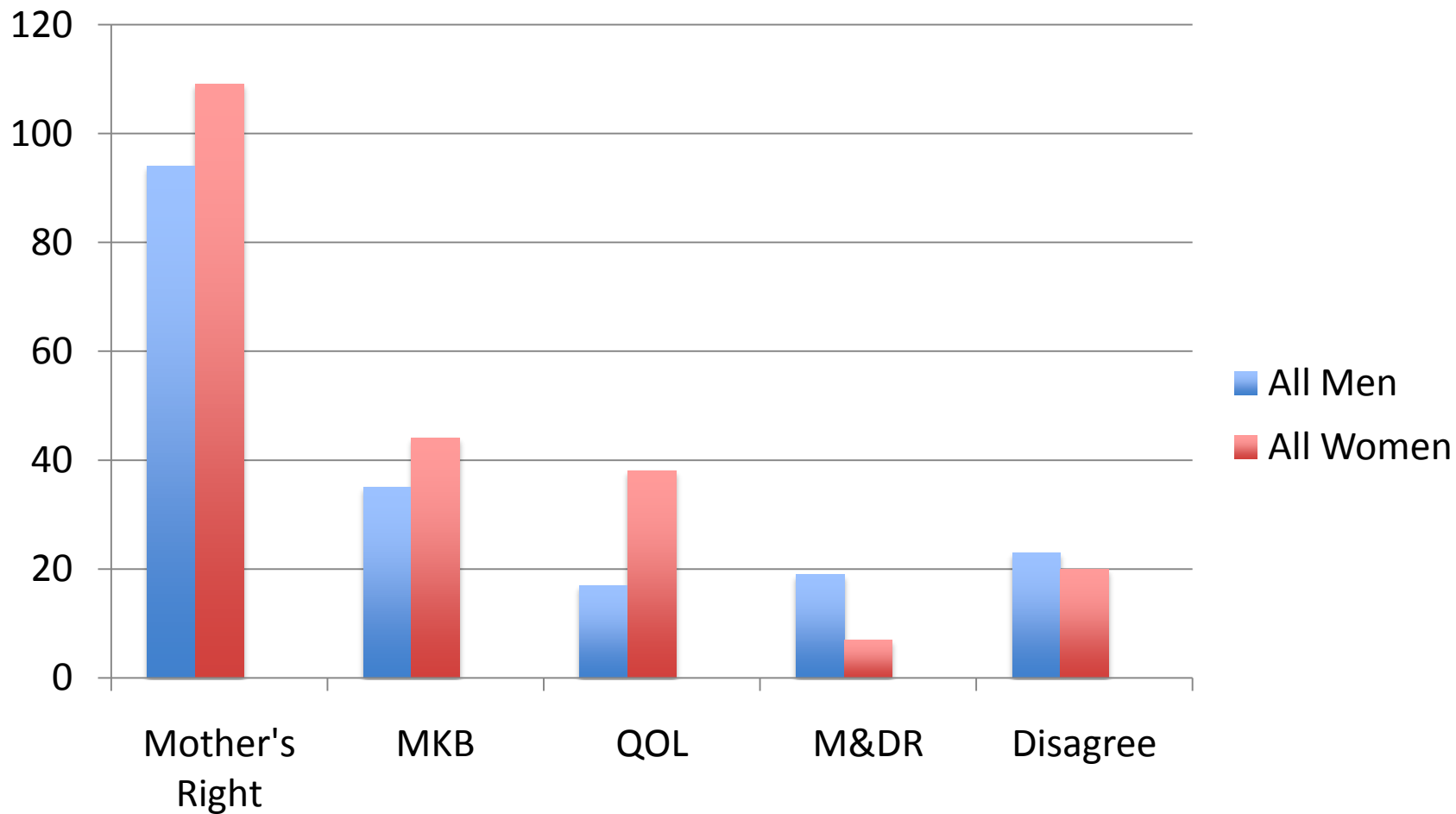
An ad-hoc group living in a specific location and who represent a variety of social and occupational backgrounds (Esterlie et al 2008).

Individuals with no strong family or personal connection to an ID person or a service or support system (Cuskelley et al 2004)

H.Y.S Categories



Mother's Right



Men's and Women's Responses

This action helps the mother, who is caring for this girl 24/7 (Rolo)

Its unlikely that Katie will ever develop a normal relationship and become pregnant (Sam)... It is important to consider the risk of rape and what would happen if the girl became pregnant (Jonathon).

This is for mother and doctor to decide (Nick)

She wants to do it because SHE wants to (Vladimir) ... The mother is trying to remove her sexuality. Sexuality is an amazing revelation ... she will always wonder what she has missed (Johnathon).

CARING MOTHERS KNOW THEIR CHILDREN BETTER THAN ANYONE IN THE WORLD (Suzanne).

There is no need for the daughter to go through the pain and misery that periods cause (Leanne)... she will never bear children (Sophie) ... There are some unscrupulous men who would still take advantage of this poor girl (Doreen).

Its really up to the mother and the doctors (Lady K)

The mother has no right to play God like that (Molly)... In a wider context this sets a dangerous precedent, which smacks of eugenics (Cheryl).

Anti Scope/Anti Rights

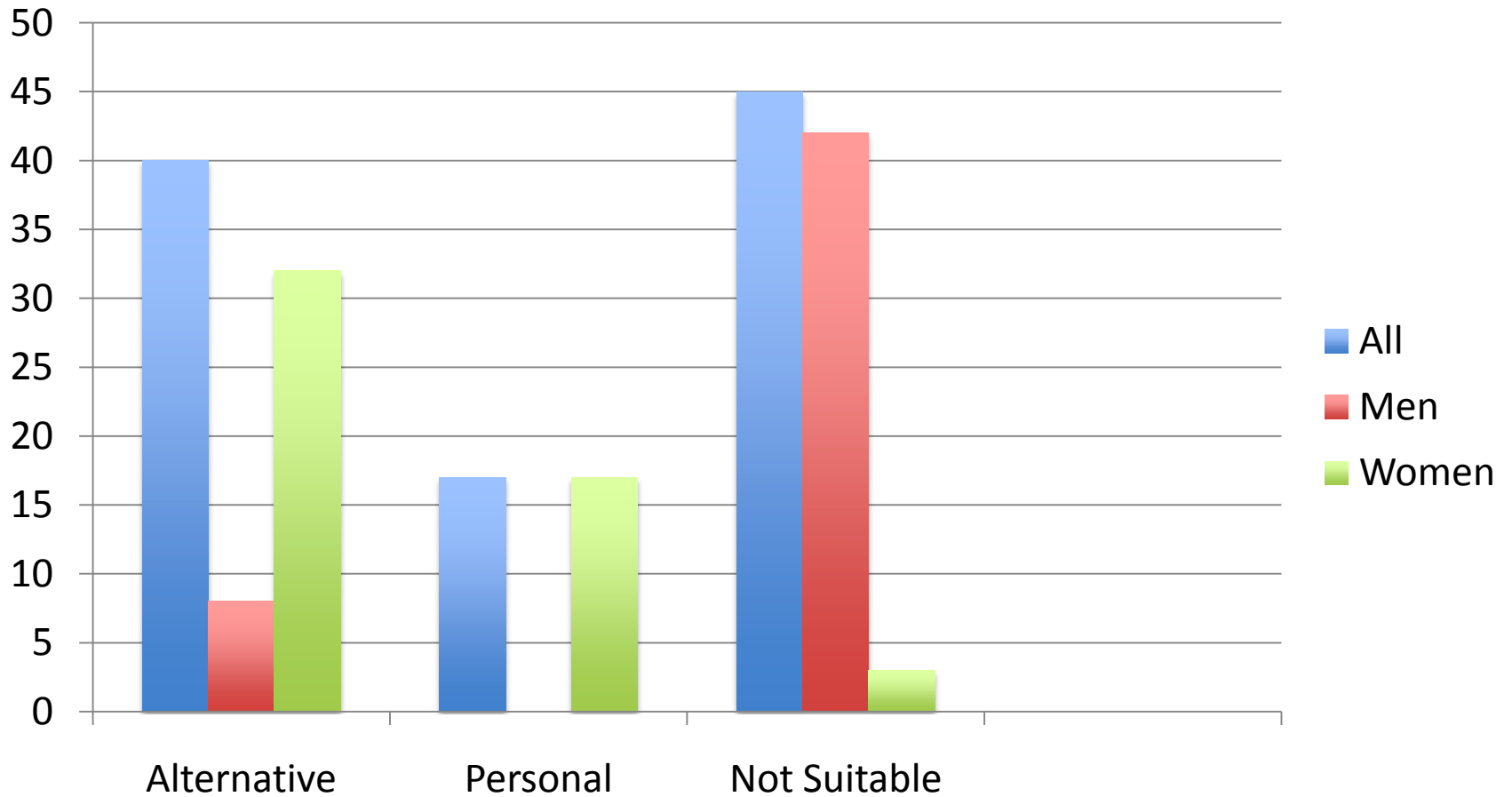
54% men posted 'interference by others' comments

"I would side with the mother 100%. Once you start getting politics involved, laws, religion and any other of the idiotic do-gooder types which seem to poke their noses in, this is when it becomes dangerous to everybody (Guy) ... It's a matter for the parent or guardian to decide – NOT social workers, social engineers or those who merely think it wrong because of their own limited views (Jack) ... Try looking after a badly handicapped, doubly incontinent girl having a period. Do this for say 6 months and then come back with your glib theoretical arguments that might be fine for an edition of 'The Moral Maze' but have no place in the real world (Andrew).

38% Women posted 'interference by others' comments

"You Human Rights Left Wing People really do go on my nerves, who are you to say what's best for the daughter? (Claire) ... They should support her instead of jumping on the pc do-gooders wagon who know nothing!!!! of her circumstances (Julie) ... Would all the people against her having an hysterectomy be there to care and look after this girl? (Claire) ... I'd like to ask Scope how much help and support they have provided to the Thorpe family over the past 15 years (Megan) ... The Human Rights Act is a complete waste of time (Leanne) ... This isn't politics, its humanity (MizEden).

Alternative/Personal Story/Not Suitable



Alternative Suggestions

8-185 Men

“A hysterectomy should not be taken lightly. There are secondary effects, both physical and psychological (Carlos)

“ How about chemically induced infertility or taking a contraceptive? (Alex) ... Why don't they give her Depo-Provera? (Tom) ... On the very, very, very remote chance that a cure is found, why not collect eggs from her and put them in cryo-storage before this operation? (James)

As it stands the chance of a 'cure' for CP are zero (Thomas)

32-184 Women

Why not just give her the pill? (Jane) ... The Depo Provera injection is well known to stop periods in a lot of women (Gemma) ... There are injections and implants she could have (Claire) ... Or fitting a coil? (Alison)

Do you think a painful operation for someone in her condition is really suitable? (Sue)

“ While I have the upmost sympathy where does this stop? (Kate) ... I feel that this is one of those debates like euthanasia – it is easy to hold the moral high ground until it affects you (Sarah)

Personal Responses

Men

24-185 comments

Should severely mentally handicapped people be allowed to have children? That is a really uncomfortable question (Benny)

Sterilisation of the “racially unfit” conducted by Hitler’s National Socialists (Tom) ... Right up to the 1970’s it was not unusual to forcibly abort women with learning disabilities as well as sterilising them (Jeremy)

Menstruation is natural and God-given. Leave nature to take its course (Michael) ... humans ‘playing god’ kept her alive in the first place (Lawrence)... It’s interference with nature, which would surely have let this poor girl die (Nik)... I believe in the human animal and sometimes a decision has to be made to alleviate any form of distress and suffering. Make the right decision for the human animal (Andy).

“ I didn’t need an hysterectomy when I was a child and neither do any other children who didn’t have disability. So this child shouldn’t be any different (Jack)

“ If she is mentally capable then the decision is hers in law (Douglas)...Such decisions should be referred to the courts (Ellis)

Personal Responses

Women

17-184 comments

- “I’m a 41 year old woman facing an hysterectomy after 20 years of hell (Glossop Goddess)... I suffer terribly (LBW) ... Please do not criticise this mother. I have had this operation done (I was young at the time) and I have never looked back (Margaret)*
- “ I get upset if I leak through onto the bedclothes (Jenny) ... When you go out anywhere you are constantly wondering if you have ‘leaked’ This poor girl can’t just nip to the toilet to “change”, her mother etc are going to have to do it for her. I can’t imagine being able to do this in the toilets in Tesco’s (Mizzdaizyduke)*
- ... Questioning minds would like to know if male children who are severely disabled have their reproductive organs cut off before puberty. Surely it is in the male child’s best interests not to have feelings... but more importantly he’s never going to father children (Victoria)*
- “I’m 15 too and my periods don’t cause me huge pain, upset or inconvenience. We’re not living in the 1950’s anymore- periods aren’t and shouldn’t be such a big issue (Sarah)*

Not A Suitable Topic for Discussion

Men 17% agreed/.5 disagreed

“Sorry BBC I think some things should not be discussed (Anthony) ... Does anyone else share my thought that this is not a remotely suitable topic for public discussion? (Steve) ... Hear, hear, if the BBC has any respect for privacy it will drop this subject quickly (Peter) ... I can't believe how low the BBC have stooped for the sake of sensationalism (Paul) ... I find this question really abhorrent BBC should be ashamed of itself (Tom)

“Since you ask, no I don't agree with you. HYS is for people to express their opinion, so it is therefore a suitable discussion topic (Harry) ... Refusal to discuss thorny issues is simply a step along the road to ignorance... should we not discuss euthanasia, abortion, sex and paedophilia because some people find it distasteful? (Tom)... I don't want to live in a society where we cannot discuss such matters and ask these questions. It is extremely important to that the wider society can come together in order to define its shared values and prevailing attitudes. I am sure we can do this (Thomas)

Not A Suitable Topic Women

- .1% (3-184) Women
- “ I find it morally wrong that we should debate this private and highly sensitive matter. (Laura)... This has become a society where reporters literally crawl under and in beds to give their sordid stories (Anne) ... Please REMOVE this topic from HYS. It does not benefit the BBC to promote discussion in such a personal matter (Mairaid)
- “I don’t agree with HYSers who say this topic should not be discussed here (MowBee) ... Surgery on a person incapable of decision-making should be subject to a great deal of public scrutiny (Jane) ... Not one of us can be sure that this worrying question wont arise in one of our families (Patricia)

Findings

1) The mother's right

24% women vs 19% mother knows best

20% women vs 9% mothers right/role

3% women vs 10% mother and Dr together

12% men vs 11% disagree

2) Alternative Strategies

17% Women vs .4% Men

3) Personal Comments

13% Men Natural/Civil law vs .9% Women physical/social exp.
menstruation

Unexpected Findings

Difficulties for GCM's with rights positions

- a trump card used to manipulate conversation rather than an aspect of a 2 way beneficial conversation
- rights and the political ends to which they are deployed

The significant *Not a Suitable Topic* finding

45 posts (rising to 62 of the 466 posts with non GCM)

- a significant and potentially damaging policing of the concept of free and open debate – strong moral position

'I know I am being hypocritical myself but this is none of our business' jerryactric, Barnsley

Conceptual Understanding

The lack of discussion about many areas of sexuality considered socially transgressive is not “born of indifference, but is rather a policed, defensive silence” (De Palma et al 2007)

Already-established codes of conduct continue to shape societal attitudes and practices

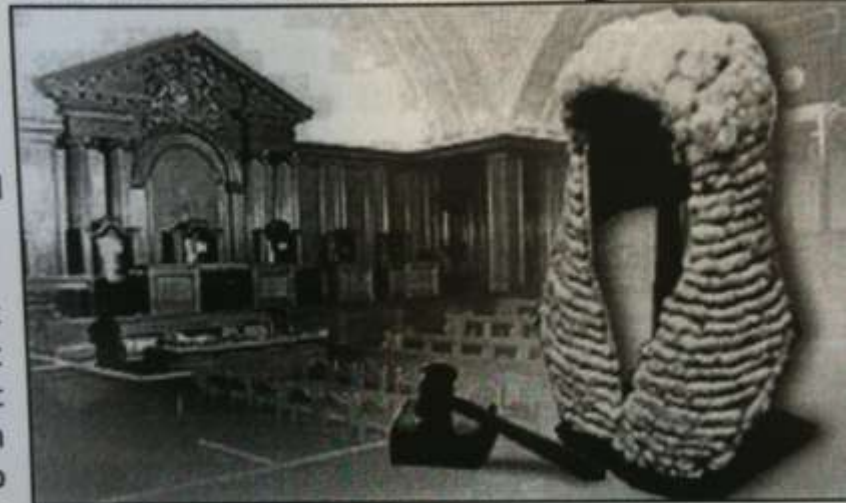
HYS comments – open up the cone of silence that surround discussions about how ID people are to secure their rights to manage their own sexual and intimate lives.

Comparison



Katie Thorpe's mother Alison wants her to avoid suffering

Down's man faces sterilisation ruling



This is the first case involving sterilisation of a man

New Zealand Example

<http://www.stuff.co.nz/national/683764>

Former care workers in masturbation claim

The Nelson Mail

Last updated 13:06 21/10/2008

Text Size

Print

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COLLIN SMITH/Nelson Mail

COMPLAINT: Nelson care worker Janet Gambell, with her husband John, is speaking out.

A group of former Nelson support workers has sparked official complaints and investigations after alleging they were ordered to help intellectually impaired people in their care to masturbate.

The company which employed the six women, New Zealand Care, has denied the claims but confirmed it is investigating them.

Five of the six women have resigned since May, largely because of disgust at the orders they said they were told they were contractually obliged to follow.

The group, which is considering laying a complaint with the Health and Disability Commissioner, met the Nelson Mail and Nelson MP Nick Smith and outlined what it described as a push by NZ Care to effectively make the workers prostitutes.

Public Service Association organiser Mike Cunliffe said the union would be laying an official complaint with NZ Care and said a personal grievance case was also possible.

"It would be fascinating to hear their explanation," he said.

Dr Smith said he had lodged an official complaint with Health Minister David Cunliffe and was seeking an independent inquiry into the issue.

"The allegations are so awful that it is difficult to believe they are true. I found all six women to be honest, genuine and totally believable," Dr Smith said.

Claire Ryan

Consultant

[Visit Claire's new website and blog »](#)

Claire Ryan specialises in the area of sexuality, relationships and intimacy and intimate support. Her work takes her all over New Zealand – running workshops, providing education to people with learning impairments, providing consultation and guidance to disability agencies. She has a particular interest in supporting people who have unique sexual behaviours.

Claire has provided support and education to the following agencies – NZ Care, Hawkesbury Trust, Northern, Central and Southern RIDCA, Nelson-Marlborough Health Board, IDEA Services, EXPLORE, Te Roopu Taurima o Manakau, and Halswell Residential College.

"Some of my future plans are to venture into the area of developing sexual surrogacy and sexual assistance for people who require a more 'hands on' approach to their support," Claire explains. "This would involve working with people within the sex industry who may be able to provide such support and services. This would be based on a model established in Sydney called **Touching Base**."

Claire's personal belief is that sexuality is a human right which has been neglected for disabled people. "Practices within many disability support agencies are de-humanising. It's as basic as the language that is used with people – words such as client, service users, patients do not acknowledge someone's gender or in fact their status as a human being!



Paul Henry

“Here's the really interesting revelation - she is in fact retarded”

“If you look at her carefully, you can make it out”

On-air apology after an order from the NZ Broadcasting Standards Authority (Dec 2009)

