Control of Reproduction by women with intellectual disabilities

Jan Walmsley Presentation to the SPRC, University of New South Wales

17 Feb 2015
The research

- Hosted and largely funded by Open University, UK
- International workshop 2010
- Historical incidence of sterilisation in UK published in Disability and Society (Tilley et al 2012)
- Podcast interviews with survivors (Iceland and Canada) and parent (England)
- Ongoing interviews with women with intellectual disabilities 2014-15
A Eugenic Legacy?

Eugenic policies which kept sexes apart, involuntary sterilisation, prohibition of marriage etc. now discredited in Western countries

‘the only remedy is to place persons so suffering under such restrictions as to make procreation impossible’

(Radnor Commission 1908)
Human Rights

- Policy now supports rights to relationships, family life and parenting

- UN Convention on the Rights of Persons with Disabilities (2006) upholds disabled people's rights to found a family and to decide on the number and spacing of their children (Article 23)

- People with learning disabilities have the choice to have relationships, become parents and continue to be parents and are supported to do so (Valuing People Now 2009: 92)

- Mental Capacity Act 2005 requires all practical steps to help person make decisions

- WHO say it is crucial that decision-making is undertaken in ways that uphold the autonomy, wishes and preferences of the individual (Eliminating forced, coercive and otherwise involuntary sterilization 2014)
Previous Research into Contraceptive use

There is comparatively little research in C21. These are the main findings:

- Sterilisation no longer widely practised in Western countries, replaced by chemical methods of contraception
- Over 50% of parents with intellectual disabilities lose custody of their children
- Women start contraception earlier and remain on it longer
- Women often do not know what they are taking and why
- Widespread use of Depo Provera
- Extensive use to manage menstruation
- ‘Just in case’ approach when women are not sexually active,
- Fear of abuse cited in some research
- No research into side effects in this population
Contraception who decides? third party survey online

Conducted in 2012, 90 responses from family members, health and social care employees, advocates
The Survey (2012)

- Small convenience sample – 90 responses
- Respondents included nurses (25%), paid support workers (19%), family (17%), advocates, doctors, social workers, academics
- Three responses from women with intellectual disabilities – no ethical approval to pursue
- Responses relating to 21 women with high support needs separately analysed
Survey Findings General

- In 15% of cases women themselves initiated discussion of contraception, majority initiated by staff, family or GP

- Reasons included woman sexually active (28%), might become sexually active (15%), fear of pregnancy (31%), management of menstruation (17%)

- Contraceptive implant (46%), combined pill (24%), mini pill (7%)

- 62% of women involved in selecting contraceptive type

- 20% said the contraception was regularly reviewed

- Lack of suitable information to involve women highlighted
Survey findings: women with high support needs (n=21)

- 38% responses from mothers,
- only one woman with intellectual disabilities initiated, most initiated by mothers
- Menstrual management (50%), fear of abuse (33%), avoidance of pregnancy risk (19%), expectation women would become sexually active (19%)
- 38% reported that contraception initiated under age 16 (cf 7% in whole sample)
- 52% had made changes since starting
- 38% had had a formal assessment of capacity to decide
I will not agree to her having a coil fitting when current one wears out because the fitting is too invasive, and I am sure there must be easier ways to control menstruation. Or even give her a chance to learn how to menstruate without the need for intervention.

As the mother of this young person I would have preferred her to have been sterilised but was told this was against her human rights as a woman. She will never have children or sustain a relationship with a man and is vulnerable to sexual abuse if not supervised.

It was decided by all parties that as she did not wish to have a sexual relationship she did not require further contraception after the effects of the initial injection had worn off.
In this particular case contraception was not needed as she herself had not wanted it and felt pushed into it by staff – ‘just in case’. Parents were not consulted by staff before the event, and were told by our daughter that she had been to the doctor's for an injection but did not really understand what it was for. Had she wished to be sexually active the responsible thing would have been for her to have contraception. We would have then taken her to see her GP for advice on the best method for her.
Focus groups and interviews with women with intellectual disabilities

Funded by Open Society Foundation, under way 2014 - 15 in Uk

15 women including those unable to consent in person

With intellectual disabilities

Who are currently using contraception

Or have stopped using contraception in past year
Questions

- What type of contraception do you use?
- Why do you use it?
- How did you choose which type to use?
- What help or support did you get?
- Have you had any problems?
Finding Respondents

- A major challenge
- Two responses to direct approach to our contacts
- Three self advocacy groups approached, none wanted to take part
- 3 responses from advocacy organisations with interest in women’s issues
- One service provider locating women who meet criteria
Method

- Easy Read Letter of Introduction
- Easy Read Consent Form
- Group meeting to explain the research and ascertain how much women know
- One to one interviews using questionnaire
- (If possible) follow up group discussion
- Skype option
Good and bad

I can enjoy sex more

Put on weight

Bleeding

Periods don’t hurt as much

Headaches

Mood change
Findings to date (one group, 9 interviews)

- Ignorance about sex makes this a difficult topic

- In focus group everyone said they were taking contraception to manage periods. In private conversation one revealed that it was because she had a boyfriend, but embarrassed to discuss in public.

- Women are prescribed contraception to help manage periods, but rarely a review to check that it is having the desired effect. Three women reported that the pill or implant had not made much difference to their menstrual discomfort.
Findings

- Women reported being prompted to seek advice by family or workers

- Five had been to GP without support to discuss contraception. May mean they do not ask the right questions, or seek follow up. ‘I am nervous talking to a doctor.’

- Five women said they did not want children. ‘I never want children. It would be too hard for me, and the social workers would take them away’.

- ‘My decision, I did not want children.’

- ‘Social worker said “no you cannot have a wain, you cannæ look after yourself, let alone a wain”. It hurts me because I love wains.’

- ‘Don’t want wains, no pills, no boyfriend’.

- ‘I said no thank you, no wains for me’

- All but one said not enough information. The exception had had sex education at school (age 32)
Meeting the sampling criteria?

- One woman appeared to confuse her medication for diabetes and (possibly) a flu jab with contraception. In the group she had appeared confident in her answer to who knows about contraception?: ‘Parents say don’t have the wains. Tablet. No wains.’ She later said ‘I got the jag as well.’ Despite help from one of the workers who knows her well, I don’t think we ever got to the bottom of what pills and injections she was taking, and why.

- 2 women claimed to use 2 types of contraceptive

- 2 women said they knew nothing about sex and babies
‘I have somebody at the minute, I always tell him to use condoms all the time. I always say use a condom or we are not having sex. He says he does not like the Lycra, and I say use it or I will walk out’.

Later in the interview ‘We have not met yet. We meet on BBM and Facebook. He lives in Liverpool. He will be coming over soon’.
Follow up

- Important to have mechanisms to follow up –

- one woman prompted to go to see her GP because her periods were still painful despite the pill – support from local worker to do this

- Advocacy organisation committed to using the results to develop educational materials
Conclusions: what does this research add?

- Confirmation that decision making about contraception is not straightforward
- Some women are actively involved in decisions to use contraception, but lacking the information to make fully informed decisions
- Medical practice sloppy in relation to information giving and review
- Health issue – women taking contraception for long periods without good reason to do so (average life expectancy is 60 for wWids)
- Lack of basic sex education even amongst younger women
- Far from a straightforward rights issue
- Women’s issues need greater prominence in research and practice
References

Sue Ledger, Sarah Earle, Liz Tilley & Jan Walmsley (in press) Contraceptive decision-making and women with learning disabilities *Sexualities*


References


Thank you for listening

janwalmsleyassociates@gmail.com