Research on sexuality and learning disability: what shapes it and what does it tell us?

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Plan

- Outline historical and current attitudes towards the sexuality of people with learning disabilities
- Look at how these have shaped research over the past few decades
- Look specifically at recent research on the sexuality of women with learning disabilities
How people with learning disabilities were generally regarded

- “Holy Innocents”
- Eternal Children

- Potentially dangerous
- Lacking in self-control
Effect of these beliefs on the sexuality of people with learning disabilities

- Their sexuality completely denied.
- Kept in a state of ignorance.
- Their sexuality over-emphasised.
- Considered promiscuous, a sexual threat to others.
Resulting in the perceived need to:

- Protect people with learning disabilities from all the sex in society.
- Protect society from all the sex that people with learning disabilities had in them.
Eugenics

- A belief system and social movement aimed at improving the genetic constitution of the human species.
- Logical conclusion of these beliefs is to prevent certain people from reproducing.
Eugenic sentiments

- “Feeble-minded women are almost invariably immoral, and if at large, usually carriers of venereal disease or give birth to children as defective as themselves.”

- “It is better for all the world if, instead of waiting to execute degenerate offspring for their crimes, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.”
Eugenic solutions

- Compulsory sterilization
- Institutionalisation
100 years ago…
Mental Deficiency Act 1913

Official categories
- Idiots
- Imbeciles
- Feeble minded
- Moral defectives

Modern equivalents
- Severe L D
- Moderate L D
- Mild L D
What changed attitudes towards sexuality of people with LD?

• 1) Liberalisation of attitudes towards sexuality generally from 1960s onwards

• 2) Adoption of normalisation principles

• 3) Availability of contraception
Current attitudes

• Still very problematic. Why?
• Lack of understanding
• Still not considered fully/genuinely adult
• Conditions of people’s lives not conducive to developing intimate relationships
• Vulnerability to exploitation and abuse
• Notion of people with learning disabilities as parents is still very challenging
Themes from the research literature: 1970s

- Emphasis on establishing the right to, and need for, sex education for people with learning disabilities
- Very strong bias on themes of heterosexual dating and marriage (Wolfensberger 1972, Lee 1972)
- Little or no attention paid to negative side of sexuality (Lowes 1977)
- Suggestions that staff could have beneficial sexual contact with clients (Greengross 1976, Stewart 1979)
- Marriage was subject of significant research interest (Mattinson 1970, Craft and Craft 1979)
Themes from the research literature: 1980s

- Much more literature
- Still need for sex education which predominates as a theme (Craft and Craft 1983, Robinson 1987)
- Reproductive rights (Chamberlain et al 1984, Roy and Roy 1988)
- Assessment tools (Brown 1980, Craft 1983)
- Development of specialist sex education materials and staff training packs (Dixon 1986, Kempton 1988)
- Policy development
Themes from the research literature: 1990s

- Attention paid to harsh reality of people with learning disabilities sexual lives (Brown 1993, Hingsburger and Ludwig 1992)
- Awareness of gender power relations (McCarthy and Thompson 1992, Burns 1993)
- Positive representation of same sex relationships (McCarthy and Thompson 1993, Cambridge 1997)
- Awareness of need for multi-cultural approach (Baxter 1994, Malhotra and Mellan 1996)
- Sexual abuse is subject of significant research interest (Brown and Turk 1992, McCarthy and Thompson 1997)
Themes from the research literature: 2000s

- Interest tails off
- Capacity to consent (Murphy 2003, McCarthy and Thompson 2004)
- Sexual abuse (Sequeira and Hollins 2003, Reynolds and Shepherd 2009)
- Reproductive health (McCarthy and Millard 2003, McCarthy 2009)
Sexuality and women with learning disabilities

- In 1999, I published a book with my research findings showing that women with learning disabilities had mainly negative and unsatisfying sexual experiences and relationships.

- Recently, I did a systematic review of the current research on same topic.
5 studies between 2011-2013

Hollomotz (2011) UK

Qualitative study of 17 women with learning disabilities

- Limited existing social networks and limited opportunities to form new relationships
- Women harboured unrealistic ideas of meeting partners in mainstream bars, clubs or dating agencies.
- Importance of day centres as a place to meet partners
- Cultural assumptions of risk and passivity are simplistic; ‘vulnerability’ has more to do with power relationships and social situations than any inherent characteristics associated with learning disability
5 studies between 2011-2013

Bernert (2011) US

Qualitative study of 14 women with intellectual disabilities

- Women had expectations of sexual autonomy, but these were often thwarted –
- by partners
- by families
- by service providers
- Most women experienced limitations on their sexual expression because of protective policies and programmes and because of their partners
5 studies between 2011-2013

Bernert and Ogletree (2013) US

- Most women had negative perceptions and negative experiences of sex; many adopted abstinence as way of avoiding negative outcomes
5 studies between 2011-2013

Eastgate et al (2011) Australia

Qualitative study of 9 women with intellectual disabilities

- Women wanted relationships with men, but found the reality of them difficult. In practice, most had found it difficult to have safe and satisfying sexual relationships.
- All had had unwanted sexual advances from people who were not their partners.
- Most had experienced sexual abuse and "repeated victimisation was a particularly striking finding" (p.229)
5 studies between 2011-2013

Fitzgerald and Withers (2011) UK

Qualitative study of 10 women with intellectual disabilities

- Despite having sexual experience, the women did not think of themselves as sexual
- Passivity was the overriding theme and they felt powerless in relation to men.
- Lack of sexual pleasure was the norm
Fitzgerald and Withers (2011)

- “The women in this study rarely appeared to expect to experience sexual desire, but acceded to pleasure-less sexual acts with men in the apparent belief that this was their role” (p.4)

- “..how little seems to have changed since the time of earlier research on this topic (e.g. McCarthy 1999)” (p.7)
Suggested reading

• Bernert, D. (2011) Sexuality and Disability in the lives of women with intellectual disabilities, Sexuality and Disability, 29, 129-141. DOI10.1007/s11195-010-9190-4


McCarthy, M. (2009) ‘I have the jab so I can’t be blamed for getting pregnant’: contraception and women with learning disabilities, Women’s Studies International Forum, 32, 3, 198-208. DOI 10.1016/j.wsif.2009.05.003

Also, look out for…


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Possible questions /topics for discussion

1. Why is far more research attention paid to the sexuality of women with learning disabilities compared to men?

2. Why do people with severe and profound learning disabilities still hardly feature in sexuality research at all?

3. How can you best work with parents to support their young adult sons or daughters with understanding relationships?

4. How to best to support men and women with learning disabilities around issues of consent?

5. What are the main concerns regarding managing relationships between people with very different levels of abilities?