

May we have sex please
tonight?

Sexuality Paper No 24

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Method

- Participatory Research Project
- Focus Group Discussions with 15 self advocates

Aim

- Inform the development of a local Relationship Policy for working with people with intellectual disability (learning disabilities)
- Encourage policy makers and practitioners to consider the concerns of people with intellectual disability who use services regarding their rights to privacy and relationships
- Encourage people with intellectual disability to speak up for their rights

Focus

- Right to privacy and relationships for people who live in residential group arrangements ie living arrangements 'organised' by a service

Historical Context

Contrasting stereotypes of sexuality of people with intellectual disability :

- a) Eternal children : innocent and asexual
(any sign of sexual interest ignored, repressed or misunderstood)
- b) Sexually deviant / promiscuous: inability to control urges
(segregation of sexes, rules and regulations to manage and protect)

Legislative / Regulation Context

- Valuing People Now
- Convention of the rights of persons with disabilities (United Nations 2006)
- UK legislation – Sexual Offences Act 2003
Mental Capacity Act 2005

Current Situation

- Lack of support for people with intellectual disability with regard to their sexuality results in a permanent state of adolescence
- Due to lack of support people to engage in sexual activity which is secretive and rushed

What people with intellectual disability say

‘Our homes have rules which do not allow our partners to sleep in our bedrooms but there should be ways around them

Especially couples who have been together for a long time are upset by these rules.

We want to do in our home whatever we like to do, that is what other people do. We want privacy and a right to sexual lives.’

‘ My boyfriend once went to my bedroom, staff came in and checked on him. The asked ‘ what are you doing here’ and told him to leave.’

‘They used to say ‘ don’t kiss your boyfriend here. Go behind the wall’

Results of such 'restrictions'

- Rushed sexual activity allows little space for careful negotiation of personal boundaries.
- Limited time to consider whether they consent to a proposed sexual act and to communicate their decision
- Inevitably people are at risk

Views on the way forward

Sometimes carers will say that a person is unable to make decisions about privacy and relationships. This is bad. You should have your own choices and make your own decisions, You should be treated as an adult. If you have no choices you have no rights. Staff should step back and let people make their own decisions.

Mental Capacity Act

- Implies people with intellectual disability in future must receive suitable information about sexuality and be given support with interpersonal relationships in order to enable an appropriate judgement about capacity.

Users Say

- A couple should have a chance to get to know about each other and talk to each other in private.
- People should be able to lock their bedroom door
- Being private is very hard if you share your bedroom

We need to understand

- It is not possible to stop people from being sexual by barring privacy
- Lack of privacy means people have no choice but to be sexually active in public places
- Lack of privacy and a safe place to meet means people engage in unsafe and rushed practices

Possible solutions

‘My boyfriend is allowed to be in my bedroom. All of us have a panic alarm in our rooms. We can call on the carers if we need to.’

Positive Risk Taking

- Safe places which facilitate privacy
- Environment which allows for the development of a relationship without interference from others

Supporting Sexuality

Focus on relationships when planning with people about their own lives, including personal and sexual relationships.

(Valuing People Now DOH 2007)

Other Issues

- Same sex relationships
- Relationship between a person with an intellectual disability and a person without a disability