The provision of sexual health care for adult women with learning disabilities

Katrin Lehmann aims to address common societal views that deny women with disabilities the right to sexuality and challenges some of these views and beliefs, focusing on the promotion of positive sexuality.

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Learning disability and sexuality

Roth and Morse (1994) define disability in general as the degree of observable and measurable physical or mental impairment. This definition puts an emphasis on impairment or defectiveness of a person in comparison to the rest of the population. The definition of learning disability has changed over the years. For example, the Department of Health and Welsh Office (1999) defines learning disability as incomplete or arrested development of mind, which includes severe impairment of intelligence and social functioning. Women with learning disabilities therefore cannot be described as a homogenous population. Each one of them is an individual with complex needs, which could have occurred as a result of trauma, sudden illness, progressive disease or congenital abnormalities. Learning disability could occur in conjunction with physical disability or in isolation. Learning disability has been categorised into mild, moderate, severe and profound, according to measured intelligence, using standardised assessment tools, for example the Wechsler Intelligence Scale (Blackburn, 2002).

The issue of sexuality in adults with learning disabilities is surrounded by myths and misconceptions among carers and professionals alike. For example adults with learning disabilities have been described as innocent about sex, hypersexual, sexually aggressive and dangerous (Owen, 1994; Roth & Morse, 1994). These are two extreme views, which have led on the one hand to a more preventative, risk-management approach (Collins & Cozens, 1999). This includes protection procedures for vulnerable adults from abuse and disease prevention of HIV and other sexually transmitted infections. On the other hand there has been a lack of formal sex education due to the view, that adults with learning disabilities are child like in their behaviour and do not require any formal sex education. In this context Roth and Morse (1994) claim, that differences in intellectual function may delay or limit the extent of sexual maturation in women with learning disabilities. However Martin (2001) disagrees, stating that disability does not usually affect fertility, and that sexual maturation occurs roughly at the same time in women with learning disabilities as it does in the rest of the population.
Attitudes and beliefs
Cooper (1995) describes the media message that sex seems to be for the young and beautiful leaving out the rest of the population including people with a learning disability. This has lead to a common societal view, which seems to deny people with learning disabilities the right to sexuality. Brown (1996) claims, that there are still service cultures, which infantilise women with learning disabilities by calling them girls and failing to address the issue of gender. Thus denying the fact, that these are adult women in the first instance who have the same rights as the rest of the population. First and foremost they are women and only secondly they are disabled. On the one hand this is due to a desire to protect vulnerable women from possible abuse. On the other hand some people believe it is morally or ethically wrong for disabled people to have intimate relationships. Johnson and Davies (1989) found, that nurses behaviours, which are based on fundamental religious values and beliefs overly prevented people with learning disabilities from forming intimate relationships. It could be argued, that this only represents one viewpoint in society and as professionals we should challenge our own views in this respect. Women with learning disabilities have been traditionally looked after by their parents and guardians or in institutional settings. Parental or carer attitudes are also vital in relation to the acceptance of sexuality in women with learning disabilities.

Thompson et al. (2000) argues, that everybody has the right to know, the right to privacy and the right to treatment as a universal human right. These basic human rights are also described in the Human Rights Act (1998), which provides limited guidance on the issue of learning disability (Leckie, 1999). On application of article 12 of the Human Rights Act (1998), men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right, which implies, but does not specify the right to have sexual relationships.

Women with learning disabilities therefore have same right as anybody else to gain information about available services. However it could be argued, that women with learning disabilities are being denied the right to adequate treatment through the lack of provision of specialist family planning clinics. There are very few examples of specialist family planning service provision for disabled women in the literature (Taylor et al., 1998). A lack of privacy and time can be seen as one of the biggest obstacles in a busy generic family planning clinic. Martin (2001) concurs, claiming that, for a woman with learning disabilities several factors must be taken into consideration, such as accessibility, communication, comprehension, compliance and continuation of support following the visit. Band (1998) suggests, that overall women with disabilities fall below the UK average for uptake of breast screening and cervical smear testing. It could therefore be argued, that any opportunity to provide health promotion and screening should not be missed by the family planning nurse.

Legal issues
The provision of contraceptive advice and guidance for women with learning disabilities is governed by a number of legal documents. Evans and Rodgers (2000) state, that protection of individuals with learning difficulties is at the heart of legal intervention, where sexual and intimate relationships are concerned. These issues are governed in the UK within civil and criminal law. Civil law has previously dealt with the issues of sterilisation and abortion in women with learning disabilities. In recent times there has been a shift from the paternalistic to a much more flexible approach, in which it has been acknowledged, that disabled people have the same feelings and longings as other people (Evans & Rodgers, 2000). However a legal right for all individuals to express their sexuality is based on the individual’s capacity to give informed consent. This creates questions about who decides the individual capacity and how much an individual has to be able to understand to give consent. The current lack of guidance has been acknowledged and the government is currently reviewing the Mental Capacity/Incapacity Bill (2004) (Department for Constitutional Affairs, 2004). This new bill provides a statutory framework to protect vulnerable people, carers and professionals, making it clear who can take decisions in which situation. The bill focuses on an assumption of capacity, making capacity decision specific, encouraging participation and supporting the right of people with learning disabilities to make what might be seen as eccentric decisions.

Owen (1994) supports this view claiming, that even those with severe learning disabilities may be competent to give informed consent if matters are explained carefully and they have been sufficiently educated beforehand to understand any implications of treatment. Within civil law health care workers can be found to be negligent if they fail to carry out their duty of care (Royal College of Nursing, 2000). The new Capacity/Incapacity Bill (2004) introduces a new criminal offence of neglect or ill treatment, against anyone who has ill-treated or neglected a person who lacks capacity.

Within criminal law, offences against a disabled person are described in the Sexual Offences Act (1956) (Blackburn, 2002). This Act operates on the assumption, that all mentally incapable individuals are vulnerable to the same degree, thus potentially denying them an intimate relationship (Evans & Rodgers, 2000). In legal terms women with learning disabilities are seen as defective, which is clearly not a politically correct term to be used. The issue of consent is absolutely crucial in this situation. The criminal law is very clear and states that any man having sex with a defective (a woman with an IQ of less than 50) is committing an offence even if she has consented (Fletcher, 1997). With the implementation of the Sexual Offences Act (2003) in England and Wales new offences in relation to adults with learning disabilities have been introduced, such as specific offences committed by care workers (Home Office, 2004). This new legislation aims to provide better protection to adults with learning disabilities while trying not to interfere with the right to a sexual life of people with learning disabilities who have the capacity to consent. This new legislation has yet to be introduced in Northern Ireland. This clearly demonstrates the difficulty for the family planning nurse in educating and guiding women with learning disabilities in the absence of evidence in relation to their cognitive abilities. By protecting the vulnerable and treating all women with disabilities the same way, the law is denying a lot of women the right to an intimate relationship. Evans and Rodgers (2000) argue that the law is not seeking to protect the vulnerable, but rather to protect society from the vision of disabled people having a sexual persona. Roles and responsibilities of the family planning nurse include:

- Holistic assessment of the client's needs.

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- An appropriate manner, attitude, confidence and knowledge in dealing with clients with learning disabilities.
- Respect for informed choices made, even if they appear to be less practicable.
- Awareness of own limitations when dealing with clients with learning disabilities (NMC, 2002).
- Liaison with professionals and informal carers involved; with the clients consent (Martin, 2001).
- Utilisation of local policies and procedures to provide clear lines of accountability and understanding (RCN, 2000).
- Confidentiality and record-keeping according to NMC (2002) guidelines.
- Provision of evidence-based practice.

Case study: Karen
Karen, a 19-year-old young woman is attending the local family planning clinic with her mother requesting contraceptive advice. Karen has been diagnosed as having a mild learning disability and epilepsy. Karen’s real name has been changed to ensure confidentiality and anonymity. On arrival at the family planning clinic, the nurse and doctor have to assess Karen’s ability to give informed consent. Her need for contraception, the implications of pregnancy on her health and coping with a child, her relationship, and her understanding of sexuality as well as the possibility of abuse have to be addressed. There are a number of contraceptive options available to Karen. These options include the combined pill, the progesterone only pill, the injection, the implant, intra uterine devices and systems all combined with barrier methods to protect her from sexually transmitted infections. The combined pill is suitable for Karen, who is mobile and does not have any additional risk factors in relation to cardiovascular disease or a significant family history. However, due to her prescribed anticonvulsants phenytoin she requires a higher dose of oral contraceptive and possibly shortened pill-free intervals. The combined pill and even more so the progesterone only pill require good memory and compliance on Karen’s part. The injection would also be suitable for Karen, with careful explanation of the possibility of irregular bleeding and the delay in the return of fertility. The implant is also suitable if Karen is happy to consent to the insertion and is prepared for her bleeding pattern to change. The intrauterine device may not be as suitable due to difficulties in insertion and heavier periods. The discussion should also include health promotion in relation to sexually transmitted infections, breast and cervical screening. Karen should also be taught to use a barrier method such as male or female condoms in conjunction with her chosen contraceptive method. In this context Owen (1994) stresses the importance of using a correct anatomical model due to the fact that if you rely on broom handles and bananas some people may think that this is where they go. Karen should also be taught assertiveness skills and how to say no to unwanted intimacy. Following this discussion, Karen decides to commence on the oral contraceptive pill at a higher dosage. Karen is taught how to take the pill, its effects and side effects and what to do if problems occur. A letter is also being sent to her GP and her neurologist with Karen’s permission to inform them of her choice. With Karen’s permission, her mother is also included and will remind Karen to take the pill correctly.

Conclusion
Due to the vast extent of this subject it is very difficult to draw a conclusion. The aim of this article was to discuss the role of the family planning nurse in the care of women with learning disabilities. In reality there seems to be limited available research evidence concerning the actual intimate relationships experienced by disabled adults in the UK, but some excellent in-depth research studies have been carried out (McCarthy, 2001; Blackburn, 2002). Results demonstrate the difficulties experienced by women with learning disabilities as a lack of privacy, knowledge, discouragement from others and the potential for abuse. There is clearly a need for further research like this and the development of clear policies and guidelines in conjunction with disabled women themselves to promote positive sexuality. In many respects Karen is a positive example due to her parental support and her opportunity to explore an intimate relationship. Many women like her will never be given this opportunity unless there are more specialist services available to them and professionals who feel comfortable to address this very important issue.

References