Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy

National Disability Authority
Údarás Náisúnta Míchumais

crisispregnancyagency

Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy

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Foreword by the HSE Crisis Pregnancy Programme

On behalf of the HSE Crisis Pregnancy Programme (formerly the Crisis Pregnancy Agency), I welcome the findings of this literature review relating to intellectual disability, pregnancy, counselling, and crisis pregnancy.

The study, which was jointly commissioned by the National Disability Authority and the Crisis Pregnancy Agency, aimed to describe the key challenges faced by women with intellectual disabilities in accessing health and social work services during crisis pregnancy. The study also aimed to identify international models of good practice regarding crisis pregnancy counselling and support services for women with intellectual disabilities experiencing a crisis pregnancy.

The comprehensive examination of Irish and international literature presented in the report reveals that there is very little research investigating crisis pregnancy among women with intellectual disability. However, the review does reveal specific challenges in relation to preventing crisis pregnancy for women with intellectual disability, such as lack of knowledge surrounding sexual relationships, increased vulnerability to sexual exploitation and lack of appropriate support services.

The review also demonstrates that sexual health care and relationships for women with intellectual disability are complicated by legal and technical issues surrounding her capacity to consent, both to medical treatment (including contraception) and to sexual intercourse. Negative attitudes to sexual activity among people with disabilities, a desire to protect women from exploitation and lack of specialised care to enable women to participate in healthcare and reproductive decision-making can compromise the level of care a woman with an intellectual disability receives.

While the review identifies many challenges and barriers faced by women with intellectual disability it also demonstrates that providing appropriate education and support services, supported by an effective legal framework, can improve such women's participation in decisions

that affect their lives and lead to better sexual health and reproductive outcomes.

It is hoped that by identifying key elements of international best practice in the delivery of sexual health and parenting supports to people with intellectual disability, this review will contribute to the development of national policy and legislative structure, standardised care protocols and accessible, tailored services. These developments will respond in the best possible way to the sexual health, pregnancy and parenting support needs of women with intellectual disability throughout Ireland.

I would like to thank the Board of the Crisis Pregnancy Agency for their involvement in the initiation, review and sign-off this important report.

The Crisis Pregnancy Agency partnered with the National Disability Authority to commission this research. I would like to thank Dr. Stephanie O'Keeffe and Dr. Roisin Morris Coyle of the Crisis Pregnancy Agency and Mary Van Lieshout and her team in the National Disability Authority for working closely together and with the author of the report in steering this project to its conclusion. I would like to thank Eilis Barry, who reviewed the report from a legal perspective.

Finally, I would like to thank the report's author, Joan O'Connor, for her hard work and commitment in synthesising and critiquing so well, such a large and diverse body of research. I share with Joan and the National Disability Authority a hope that this report will open up the discussion about issues relating to sexual health, crisis pregnancy and parenting among those working with people with an intellectual disability.

Caroline Spillane
Director
HSE Crisis Pregnancy Programme

Foreword by the National Disability Authority

The National Disability Authority is pleased to present the Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy, which was jointly commissioned by the National Disability Authority and the Crisis Pregnancy Agency. The review offers a valuable contribution to policy and practice. The identification of good practice in other jurisdictions in counselling and support services for women with an intellectual disability experiencing a crisis pregnancy offers important learning for both the future design and enhancement of existing service provision in Ireland. Current research suggests that the number of women with intellectual disability having children is increasing, which makes it all the more important that adequate and appropriate supports are in place to respond to need.

The research also focuses on areas which are very relevant to the legislation on legal capacity to enable Ireland comply with Article 12 of the UN Convention of the Rights of Persons with Disabilities. The Convention provides that people with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life. The review looks at how the capacity of women with an intellectual disability to consent to medical treatment decisions, and how their capacity to consent to sexual relations, are currently legislated for in Ireland and in other jurisdictions. The question of capacity to sexual relations raises complex questions, where the breadth of information and clarity of discussion in the review offers important guidance for future direction on this challenging issue.

In comparing the situation in other jurisdictions, the review highlights that there are no simple solutions to these issues. The legal and support frameworks need to get the balance right between supporting and enabling women with intellectual disabilities to consent to their own healthcare and sexual relations decisions, and protecting them from sexual exploitation and abuse. The review offers useful information and analysis to support policy consideration in this area.

This review also covers a range of other issues relating to the practical experiences of women as parents with an intellectual disability. This

includes the role of family members in support networks, alongside formal supports, and the importance of appropriate sex education programmes. In addition, the review covers the pregnancy experiences of women with an intellectual disability, which provides an important human dimension alongside legislative considerations. This work complements National Disability Authority research on the experiences of women with disabilities in pregnancy and early motherhood (2010). The findings of the review should be of interest to a wide range of stakeholders and will provide an important evidence base for shaping their deliberations on how best to support women with an intellectual disability.

Ms. Siobhán Barron
Director
National Disability Authority

About the author

Joan O'Connor graduated with an MSc in Applied Social Research in 2001 from Trinity College, Dublin and since then has worked as a social researcher in Women's Studies, School of Social Justice, University College Dublin, and as an independent researcher in Ireland and internationally. She has worked on a range of research projects in the areas of gender and disability, crisis pregnancy and disability, violence against women, gender and equality, social policy, women's adult education and globalisation. She is currently working as a researcher in the Centre for Disability Studies, School of Psychology, in University College Dublin carrying out research on disability and abuse.

Acknowledgements

I am very pleased to have carried out this research on behalf of the Crisis Pregnancy Agency and the National Disability Authority and would like to commend them, in particular Dr. Stephanie O'Keeffe and Mary Van Lieshout, for their guidance, and vision in prioritising knowledge development and dissemination in this area. I would also like to sincerely thank Catherine Conlon, who acted as research advisor and provided me with invaluable support and advice throughout the research process. I hope that this work will provide a useful information resource for policy makers and service providers, and assist in our understanding of the development of appropriate health and social care services for women with intellectual disability who are experiencing crisis pregnancy.

The views expressed in this report are those of the authors and do not necessarily reflect the views or policies of the sponsors.

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Glossary of terms

Enduring Power of Attorney: A person with the requisite capacity may execute an enduring power of attorney ("EPA"), giving another person the power to act on their behalf in the event that they lose mental capacity. The decisions which may be made may relate to the person's property or affairs and/or "personal care" decisions.

Learning Disability: including the presence of significant intellectual impairment; with deficits in social functioning or adaptive behaviour; which are present from childhood (Foundation for People with Learning Disabilities, UK).

Learning Difficulties: refers to individuals with intellectual impairments and used by the UK self-advocacy movement (Hollomotz, 2009).

Intellectual Disability: involves a greater than average difficulty in learning. A person is considered to have an intellectual disability when the following factors are present: intellectual functioning is significantly below average; there are difficulties with everyday life skills and the condition is present from childhood (18 years or less) (definition used by Inclusion Ireland).

Developmental Disability: refers to lifelong limitations in intellectual and adaptive functioning initially identified in people younger than 18 years. [1]

Mental Retardation: Intellectual disability is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18 (American Association on Intellectual and Developmental Disabilities, AAIDD).

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1 American Association on Mental Retardation (2002) Mental Retardation definition, classification, and systems of supports. 10th ed. Washington DC: American Association on Mental Retardation.

Executive summary

The Crisis Pregnancy Agency [2] and the National Disability Authority commissioned this systematic review of Irish and international literature to identify international models of good practice regarding crisis pregnancy counselling and support services for women with an intellectual disability experiencing a crisis pregnancy. A further aim of this review was to inform the future development of guidelines for crisis pregnancy counsellors and GPs on providing appropriate and accessible support to people with an intellectual disability who are experiencing crisis pregnancy.

For the purpose of the review, a crisis pregnancy is defined as "a pregnancy which is neither planned nor desired by the woman concerned and which represents a personal crisis for her". [3] This definition includes the experiences of those women for whom a planned or desired pregnancy develops into a crisis over time due to a change in circumstances. It is important to state that, within the review, not all pregnancies experienced by women with an intellectual disability are assumed to be a crisis pregnancy.

The main findings and commentaries of the review of the literature include the following:

- The review of literature demonstrated international legislation, structures and codes of practice on capacity to consent of an individual with an intellectual disability incorporating consent to medical treatment decisions. While there is protective legislation internationally addressing capacity to consent to sexual relations for this group, this area remains less developed in relation to assessment of capacity to consent. In addition, there was only one study retrieved over the course of the review relating to crisis pregnancy among individuals with an intellectual disability, as defined by the Crisis Pregnancy Agency.

2 Since this review was commissioned the Crisis Pregnancy Agency has been integrated into the Health Service Executive (HSE) and is now the HSE Crisis Pregnancy Programme. It is a national programme working within the Children and Family Social Services Care Group in the HSE.

3 Crisis Pregnancy Agency definition of a crisis pregnancy, as set out by the Statutory Instrument, S.I. No. 446 of 2001, the Crisis Pregnancy Agency (Establishment) Order, 2001.

- The pattern of contraceptive use amongst women with intellectual disability differs widely from that of the non-disabled population. Longstanding research confirms the Pill, Depot Medroxyprogesterone Acetate and IUDs are the only methods used by most women with learning disabilities, with barrier methods being reported as unheard of. It has been argued that the prescribing of these particular methods of contraception assumes that women with learning disabilities are incapable or unreliable when it comes to contraceptive decision-making and managing their fertility (McCarthy, 1999). As such, decisions surrounding the use of contraception may be made by others on behalf of the woman.

- International models of best practice and related supports regarding capacity to consent to medical treatment among women with an intellectual disability are considered, including the functional approach to capacity, providing for longer consultation periods with primary care practitioners, the provision of appropriate sex education and resources and the adoption of an individualised, person-centred, multidisciplinary approach to sexual health care for persons with intellectual disability.

- Legislation on capacity to consent to sexual relations exists in other jurisdictions, and varies in the degree of protection provided versus autonomy allowed. Laws that prohibit sex with people deemed unable to consent to sex are based on the need to protect individuals with an intellectual disability as they are assumed to lack capacity to consent to sexual relationships. In Ireland Section 5 of the Criminal Law (Sexual Offences) Act 1993 falls under this category and serves to criminalise sexual activity with a person who has a 'mental impairment' and who is not married. Thus, it may be an offence to engage in sexual activity with a person with an intellectual disability, even if the person consents.

- The review considers the complex area of capacity to consent to sexual relations and the protective legislation that exists in

international jurisdictions including laws which prohibit sex with people deemed unable to consent to sex, laws which incorporate a functional approach to assessment of capacity to consent to sexual relations, generic laws applying to sex without consent and laws which prohibit specific sexual relationships.

- There is a lack of empirical evidence on the individual experience of crisis pregnancy, pregnancy and childbirth among women with intellectual disability, to inform professional practice. There is limited research related to how a woman with intellectual disability conceptualises her pregnancy and whether it was unplanned, unwanted or a crisis for her. The research that does exist suggests that the number of women with intellectual disability having children is increasing and that when a woman announces her pregnancy, the reactions of people close to her are almost exclusively negative. Other challenges faced by women with an intellectual disability experiencing pregnancy and parenthood include accessing sexual health information, accessing sexual health services, inadequate information and negative attitudes to pregnancy and parenthood among service providers and the wider community.

- The review considers the importance of early presentation to medical services when a woman with an intellectual disability discovers her pregnancy. Furthermore, it considers pre- and post-natal supports for women experiencing pregnancy, as well as supports for their families and carers.

- A consistent finding in the international literature is that mothers with intellectual disability experience poverty, anxiety and social isolation and tend not to have the necessary supports in place to cope with difficulties that they encounter as parents. Furthermore, the research has established the importance of family and social support networks as well as information and education in assisting mothers with an intellectual disability in raising their children.

- The review considers the literature relating to how the family, social networks, carers and professional services can facilitate women with an intellectual disability to achieve the best outcomes for themselves as parents and for their children.

1.0 Introduction

1.1 Introduction

The Crisis Pregnancy Agency and the National Disability Authority commissioned this systematic review and critique of Irish and international literature relating to intellectual disability, pregnancy, counselling, and crisis pregnancy. The study aimed to describe the key challenges faced by women with intellectual disabilities in accessing health and social work services during crisis pregnancy. The study also aimed to identify international models of good practice regarding crisis pregnancy counselling and support for women with intellectual disabilities.

1.2 Research aims

The research had the following aims:

- To provide a synthesised and summarised overview of key debates, issues and findings highlighted in theoretical and research literature on intellectual disability, counselling, pregnancy and crisis pregnancy.

- To compare key international debates, issues and findings with issues arising for Irish women with intellectual disabilities experiencing crisis pregnancy.

- To generate an understanding of the factors that contribute to an unplanned pregnancy for women with an intellectual disability.

- To explore the level and range of risk factors - such as age, relationship status, socio-economic and cultural factors - that are related to adverse outcomes.

- To identify national and international peer-reviewed literature exploring the impact of a crisis pregnancy on women with an intellectual disability, including the direct and indirect effects of the pregnancy.

- To describe the challenges and oppressions encountered by women with intellectual disabilities experiencing crisis pregnancy, as well as revealing the ways in which women and their families/carers have responded to these challenges.

- To identify national and international good practice models relating to crisis pregnancy counselling and supports for women with intellectual disabilities. This will include identification of:
  - existing policy and practice guidelines on this topic in other jurisdictions and their relevance/applicability to the Irish context
  - legislation, structures and support mechanisms for women with intellectual disabilities in relation to pregnancy
  - guidelines for counselling for women with intellectual disabilities
  - existing supports for people with intellectual disabilities as parents, and involvement of family members where programmes/services target them.

- To draw out recommendations from the literature review that will contribute to the development of guidelines for general practitioners and crisis pregnancy counsellors supporting women with an intellectual disability who are experiencing crisis pregnancy.

1.3 Guiding principles underpinning review

Crisis pregnancy is defined as 'a pregnancy which is neither planned nor desired by the woman concerned and which represents a personal crisis for her' (Crisis Pregnancy Agency, 2007).

The Crisis Pregnancy Agency understands this definition to include the experience of those women for whom a planned or desired pregnancy develops into a crisis over time due to a change in circumstances. It is essential to stress that not every pregnancy experienced by a woman with an intellectual disability will be experienced as a crisis by her, while it may be perceived as a crisis by family members and/or carers.

Current protective legislation, i.e. Section 5 of the Criminal Law (Sexual Offences) Act 1993 criminalises sexual intercourse with a person who has a 'mental impairment' and who is not married. The legislation has implications, therefore, for women with intellectual disability and their experiences of pregnancy as it does not recognise that a pregnancy for a woman with an intellectual disability (who comes within the definition of mental impairment [4]) may not be experienced as a crisis.

The need to root policy approaches in human rights legislation, and anti-discrimination legislation has been recognised (Whitehead, Curtice, Beyer, McConkey and Bogues, 2008). The UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities and the Optional Protocol to the Convention [5] entered into force on 3 May 2008 was signed on behalf of the State on 30 March 2007. However, it has not yet been ratified. The Convention requires States to 'adopt all appropriate legislative, administrative, and other measures for the implementation of the rights' (Article 4 (1) (a)) recognised in the Convention. In particular, Article 23 (1) (a) of the UN Convention recognises the 'right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses'. [6]

There are two key perspectives on disability that have informed policy-making, social provision and legislation. Over the last twenty years the social model of disability has become central - its focus is on the inadequacies of social, environmental, political and economic factors in society that restrict the full participation of people who have impairments, failing to accommodate their needs. This represents a shift in thinking about disability, with its emphasis on political and economic processes that generate disabling environments. Prior to this a medical model of disability had prevailed. The focus within a medical model is

4 Section 5(5) defines mentally impaired to mean a disorder of the mind, whether through mental handicap or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life or guarding against serious exploitation.

5 General Assembly Resolution of 13 December 2006.

6 Article 12(2) provides that state parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

on how impairments affect functioning and participation: the medical model views disability as an individual problem that needs to be 'cured'. Policy responses based on this model often led to people with disabilities experiencing social exclusion, low self-esteem and discrimination.

According to McCarthy (1999) the effect of the medical ideology has been to define people with learning disabilities in terms of what is wrong with them. In recent years, ideologies and services have changed and the social model of disability has been increasingly influential in the learning disability field. Therefore, attention has increasingly been paid to the effect society has had on people with learning disabilities.

Feminist scholars have stressed that listening to the stories of women with intellectual disabilities is a crucial first step in the process of challenging existing stereotypes and revealing gaps in our understandings of their lives (Traustadottir and Johnson, 2000).

In the current review every effort has been made to include empirical research with women with intellectual disability - to include their wishes, expectations and needs in relation to sexuality and pregnancy. The research is underpinned by the principles and perspectives detailed above, which informed the critique of the literature.

1.4 Methodology

A systematic literature review, including theoretical and empirical research - both quantitative and qualitative - was undertaken. The approach involved systematic literature search techniques, consistent, well-justified and clearly-stated inclusion criteria, a synthesis of qualitative and quantitative evidence, attention to substantive issues, and attention to methodological issues.

1.4.1 Inclusion criteria for literature

- Range of perspectives: Incorporate perspective of a social model of disability as well as the traditional medical model and have regard to perspectives emanating from feminist, equality and human rights approaches.

- Study types: Qualitative and quantitative studies, including surveys, in-depth case studies, cross-sectional, longitudinal work and policy reviews/analyses.

- Reliable: Rigour applied in application of the methodological approach used and in analysis of the data.

- Valid: Arguments, findings and recommendations are supported by empirical evidence.

- Context: Studies from cultural/economic settings where the level of economic and social development makes living standards and social and public policy substantively comparable with Ireland.

- Substantive issues: Address all of the substantive issues outlined in the aims and research questions set out above, as well as other issues identified as relevant to the topic through the review.

- Timeframe: 1998 - 2008 inclusive, as well as any key texts before this period.

1.4.2 Search techniques

A comprehensive bibliography was prepared; general searches were conducted for the purpose of identifying key information to inform each of the topic areas, and ultimately to inform guidelines and policies to support women with intellectual disabilities and their experiences of crisis pregnancy.

The review incorporated theoretical literature and empirical research. The methods of identifying literature involved:

- Searches of computerised databases such as, Pubmed, Scopus, ERIC; Oxford Journals Online; PsycINFO; PsycArticles; Nursing and Allied Healthsource (Proquest); Francis; Oxford Journals Online; Social Science Citation Index; Science Direct; Sociological Abstracts; Wilson OmniFile Full Text; Wiley Interscience; LegalTrac; Murdoch's Irish Legal Companion; AMED; British Nursing Index and Archive.

- Searches by publication type, which covered the following disability related journals: British Journal of Learning Disabilities; Disability and Society; Disability Studies Quarterly International; Education and Training in Mental Retardation; Journal of Disability; Journal of Applied Research in Intellectual Disabilities; Journal of the Australian Society for the Study of Intellectual Disability; Journal of Disability Policy Studies; Journal of Intellectual and Developmental Disability (Aus/NZ); Journal of Intellectual Disabilities; Journal of Intellectual Disability Research; Learning Disability Practice; Learning Disability Review; Learning Disability Today; Mental Retardation; Developmental Disabilities Research Reviews; Scandinavian Journal of Disability Research; Sexuality and Disability; The Frontline of Learning Disabilities; Tizard Learning Disability Review.

- Other journals: Medical Law Review; International Journal of Law, Policy and the Family; Journal of Adult Protection; Feminism and Psychology; Psychological Medicine; Journal of Family Planning and Reproductive Health Care; Journal of Nursing and Midwifery.

- Additional searches performed using the "Related Articles" feature of PubMed and the "References Cited" feature of Scopus.

- Key web-sites: state departments, statutory bodies, research organisations, disability rights organisations, women's organisations and other relevant non-governmental organisations.

- A PowerPoint presentation, which was the only available source of data for relevant research not yet published.

- Internet searches, using terms such as intellectual disability, learning disability, mental retardation, mental impairment, and developmental disabilities. These terms were combined with key words, such as pregnancy, counselling, sexuality, sexual health,

contraception, sexual offences, sexual abuse, capacity, consent. Relevant retrieved citations were approximately 200 papers published between 1990 and 2009.

Nursing Programme personnel providing intellectual disability courses at third level (DCU, Dundalk IT, Letterkenny IT, St. Angela's College, Sligo, TCD, UCC, UL, Waterford IT) and other nursing programme personnel (UCD, NUIG) were contacted via email to find out if they were aware of good practice in supporting women with intellectual disabilities experiencing pregnancy.

Key international researchers and research institutes in the field were contacted for copies of articles and for other information as well as relevant organisations, for example, fpa (family planning association) in London.

1.4.3 Limitations

The following issues were identified in the literature:

- The majority of empirical work is carried out with women with mild to moderate learning disabilities. Dotson, Stinson and Christian (2003) point out that women with more severe disabilities, i.e. lower cognitive abilities and verbal skills, are routinely absent from sexuality research studies due to a lack of appropriate tools and research designs.

- Studies on sexuality and intellectual disability which have not taken into account different levels of disability have found overall lower levels of sexual activity, which may be due in part to the lower sexual activity of people with moderate and severe intellectual disability (Conod & Servais, 2008).

- Data regarding incidence rates of unplanned pregnancies is either lacking, dated, or restricted to certain subgroups (e.g., institutionalised) that are not representative of the larger population.

- Differences in definitions of intellectual disability and in disability services make it inappropriate to generalise data across countries (Servais, 2006).

- There is a paucity of studies that have assessed what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse, as well as affective relationships, marriage, and child-raising. Also, the factors of possible influence on these variables have not been documented, e.g. disability level, life milieu, previous sex education, gender (Conod & Servais, 2008).

- In general people who participate in research studies are those who are known to disability organisations and health and social care services, and therefore participants do not include people with intellectual disability who have not been identified and referred to services.

1.5 Population with an intellectual or learning disability

The 'First Results' published on the 2006 National Disability Survey indicate that there were 71,600 people with an intellectual and learning disability in Ireland. Of these 61% were male (43, 676) and 39% were female (27,924). 70% - or 50,120 people - had been diagnosed with an intellectual disability. Table 1 below presents data on the age and level of disability profile for women up to age 54.

Table 1: Females with an intellectual and learning disability, level of difficulty in every day activities by age group (age up to 54 only is included).*

	Level of difficulty in everyday activities				
Age group of females	Just a little	A moderate level	A lot of difficulty	Cannot do at all	Total persons
Total females	5,200	9,600	9,300	4,100	28,100
0-17	1,342	3,840	3,422	500	9,076
18-34	1,264	2,208	2,232	1,242	6,913
35-44	681	1,037	893	595	3,203
45-54	681	941	1,079	566	3,260

* The figures in this table have been extrapolated using percentages presented in Table 19.1 of the National Disability Survey. Due to rounding, the sum of the age categories may not equal the total.

There were 25,613 people registered on the National Intellectual Disability Database (NIDD) in Ireland in April 2007 (Kelly, Kelly and Craig, 2007).

Data of relevance from the National Intellectual Disability Database include:

- Of the 25,613 people registered on the NIDD, 43.5% were women (11,164 individuals); of these, 10 per cent were aged between 15 - 19 years, 25 per cent were aged between 20 – 34 years and 31 per cent were aged between 35 – 54 years.

- 64 per cent of all children and adults with intellectual disability (16,366 individuals) live at home with parents, siblings, relatives or foster parents.

- 32 per cent (8,262 individuals) are in receipt of a full-time residential service.

- 96.5 per cent of people (24,729) are availing of at least a one-day programme. Of this group, almost 33 per cent (8,125) are in full-time residential placements and 20 per cent (5,028) are in receipt of residential support services such as respite care.

- 77 per cent (19,799) of people avail of one or more multidisciplinary support service. The most commonly availed of services by adults are medical, social work and psychiatry services.

- There has been an increase in the number of people with intellectual disability living full time in group homes within local communities; this figure has more than doubled between 1996 and 2007.

1.6 Definitions and their meaning and usage

Intellectual disability is a term used to describe an incredibly diverse group of people. There is agreement that intellectual disabilities should be defined as a developmental difficulty involving significant impairments of intellectual and social functioning/adaptive behaviour. There are debates, however, about the degree to which all areas of social functioning need to be impaired (Murphy and Clare, 2003).

A word of caution is needed in relation to the literature about people with intellectual disabilities. Various terms are used to describe people with intellectual disability, reflecting the differences in acceptable terminology and different criteria used in various countries. These terms include mental retardation, intellectual disabilities, developmental disabilities, learning disabilities, learning difficulties and mental impairment. For the purposes of this review, intellectual disability is used; when reporting research findings the terminology adopted by the particular author(s) is used.

Table 2 below outlines the main terms used in international literature.

Table 2: Terminology

Terminology	Meaning and usage
Developmental Disabilities (DD)	Refers to lifelong limitations in intellectual and adaptive functioning initially identified in people younger than 18 years* Used in the United States, Canada
Learning Disabilities	Including the presence of significant intellectual impairment, with deficits in social functioning or adaptive behaviour, which are present from childhood (Foundation for People with Learning Disabilities, UK) Used in the United Kingdom
Learning Difficulties	Refers to individuals with intellectual impairments Used by the UK self-advocacy movement (Hollomotz, 2009)
Intellectual Disability	Intellectual disability involves a greater than average difficulty in learning. A person is considered to have an intellectual disability when the following factors are present: intellectual functioning is significantly below average; there are difficulties with everyday life skills and the condition is present from childhood (18 year or less) Used by Inclusion Ireland Used in Ireland
Mental Retardation	Intellectual disability is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18 (American Association on Intellectual and Developmental Disabilities (AAIDD)) Used in the United States

* American Association on Mental Retardation (2002) Mental Retardation definition, classification, and systems of supports. 10th ed. Washington DC: American Association on Mental Retardation.

1.7 Heterogeneity

People with intellectual disabilities are not a separate, homogeneous group of human beings who think, feel and act in a similar fashion. Their individual likes, dislikes, choices, talents, strengths and weaknesses are varied, as elsewhere in society (Ontario Ministry of the Attorney General, 2005). Intellectual and adaptive functioning of people with intellectual disability varies widely, hence, so does their capacity to function independently (Schalock and Luckasson, 2004). The variation between different individuals within the same group cannot be overstated (Murphy and Clare, 2003). For example, the overwhelming majority of people with intellectual disabilities have difficulties that are subtle and are not easily recognised (Emerson, Hatton, Felce and Murphy, 2000). Only a very small proportion is unlikely to be able to use verbal language or to carry out simple tasks of everyday living (such as eating, washing and dressing) without support (Hogg and Seba, 1986). This heterogeneity must be considered when deciding the relevance of general statements about people with intellectual disabilities.

1.8 Level of disability

Research that has been carried out on sexuality and women with intellectual disabilities has for the most part neglected to include consideration of the sexual needs and feelings of women with more severe disabilities (Downs & Craft, 1997). Historically, it was considered that the severity of such women's disabilities would override all and any aspects of their sexuality. According to McCarthy (2002), for most people with intellectual disabilities, it is the case that a profound intellectual impairment and the associated life-long dependency on others means that they are unlikely to be in a position to engage in consenting sexual relationships with other people. Understanding sexuality in its wider form, though, including 'feelings of love and sexual arousal, understanding what touch does and does not give pleasure, masturbation, sexual health, self-awareness and self-image, identity, communication, personal development, gender issues and age appropriateness' are relevant for people with profound and multiple disabilities as they are for other people (McCarthy, 2002: 92). The research that has been carried out for the most part relates to the heterosexual experiences of mainly white women with mild

and moderate intellectual disabilities in early and middle adulthood (McCarthy, 2002: 93).

1.9 Attitudes towards women with intellectual disabilities and sexuality

Until the 1960s there were negative and repressive attitudes towards the sexual expression of people with intellectual disabilities, whether they lived at home or in the community (Kempton and Kahn, 1991). It has been argued that in the past many disabled women have been violated by the eugenics movement and have been deprived of their rights to bodily dignity and integrity through physical, communication and clinical barriers to obstetrical and gynaecological services; involuntary sterilisation; forced abortion; sex segregation by placing women in institutions; over-use of long-acting contraceptives; and the loss of child custody (Waxman-Fiduccia, 1996). Both in Europe and in the US women with intellectual disabilities were feared and seen as a threat to society; their reproductive rights were taken away from them, as it was believed that they were 'unfit' to be mothers and that they would also give birth to children with disabilities.

According to Atkinson and Walmsley (1995) the institutional era was characterised by the loss of, or rejection by, families at the time of admission, and by the strict separation of the sexes within institutions. A policy of protection of people with learning disabilities was in existence. In relation to women, this meant that the practice was to prevent sexual relationships, which might result in the birth of unwanted and possible defective children. Closure of large institutions and the move to community living in many countries, which has occurred over the past twenty years, has allowed people with intellectual disability to enjoy greater freedom in their lifestyle choices, including establishing an intimate relationship and having children.

However, Atkinson and Walmsley (1995) argue that it is possible that a different sort of segregated living is emerging. The authors report that accounts from women suggest that the nature and quality of relationships can be restricted through prolonged enclosure, not only with the family but also in schools, hostels and group homes.

McCarthy (1999: 44) notes that two major ideology changes occurred over the past few decades, which have transformed services provided for people with learning disabilities. These are the adoption of the principle of normalisation, which has had a huge impact on services, and the growth of the self-advocacy movement.

While many positive changes have occurred, women with intellectual disabilities still face conflicting stereotypes, which portray them as either asexual, childlike and dependent or oversexed, undiscriminating and 'easy' (Tilley, 1998; Williams & Nind, 1999). Dotson et al. (2003) argue that these stereotypes are harmful because they lead either to the belief that the sexual expression of a woman with an intellectual disability can be ignored or that it must be suppressed.

Women with intellectual disability have the same sexual needs, rights and responsibilities as other women (McCarron and Kathryn Pekala Service, 2002). According to Eastgate (2008), community attitudes make it especially difficult for women with intellectual disability to achieve appropriate sexual expression. Sulpizi (1996) asserts that denying women with intellectual disability access to information regarding their sexuality because of their dependence on others denies them a basic human right. Eastgate (2008) notes it has been observed that for most of the issues relating to women's sexual health needs, including contraception, safe sexual practices, pregnancy and parenting, appropriate education and adequate social support can significantly improve their situation.

Empirical research on attitudes towards intellectual disability and perceived barriers to services revealed the following issues:

- Murray & Minnes (1994), writing in the Canadian context, argue that in general attitudes are becoming less conservative, that is, a wider range of sexual behaviours are now regarded as acceptable than was previously the case.

- Heyman & Huckle's (1995) research in the UK has demonstrated that informal carers have felt that adults with intellectual disability were not interested in sexual relationships, not able to understand them, not capable of acting responsibly, at risk of exploitation or a danger to other people.

- According to Aunos & Feldman (2002)[7] workers, professionals and parents of persons with intellectual disability are still strongly against procreation and in favour of sterilisation; these negative attitudes are associated with outdated and prejudicial practices, particularly with respect to parenting.

- Special education teachers and university students hold more positive attitudes towards sexuality and sexuality education programs than parents and service workers (Aunos & Feldman, 2002).

- In one US study, there was substantially less support for a normalised life experience with respect to sexual behaviour for individuals with intellectual disabilities than in other areas (Scotti, Slack, Bowman and Morris, 1996).

- Parenthood by people with moderate intellectual disabilities was considered less positively than other aspects of sexuality by parents and staff groups in attitudinal research conducted in Australia (Cuskelly & Bryde, 2004). [8]

- Members of the general public in research conducted in France (n=367) considered that adults with intellectual disabilities' sexual relationships were more acceptable when contraception was being used. The participants' main concerns centred on the consequences of sexual relationships, and not on the sexual relationships per se; sexual relationships that could lead to procreation and parenting among people with intellectual disability were not judged acceptable, even if the child could be cared for by a person without an intellectual disability; sexual relationships were judged to be moderately acceptable where the person with an intellectual disability was autonomous, the

7 Based on a review of literature from many different countries relating to attitudes towards sexuality, sterilisation, procreation and parenting by people with intellectual disability.

8 Sample included parents of an adult with intellectual disability (43); support staff (62) and community sample (63).

partner was the same age, and also had an intellectual disability, and the relationship was a protected one (Esterle, Munoz Sastre and Mullett, 2008).

- Research in Canada (Owen, Griffiths, Feldman, Sales and Richards, 2000) demonstrated that people with intellectual disability themselves still seem to have conservative attitudes towards sexual intercourse and homosexuality.

- Llewellyn & Brigden (1995), writing in the Australian context, found that if family members, service workers, and significant others express negative attitudes and discourage independence then the cooperation and competency of parents with intellectual disability may be adversely affected. Conversely, they note that when there is an attitude of empowerment of the family, supports and services are generally well received.

- Social service providers (n=216) in a Canadian study tended to have moderately liberal attitudes to the sexual lives of people with intellectual disability; staff of the outpatient treatment services revealed the most liberal and positive attitudes towards the sexuality of individuals with intellectual disability (Bazzo, Nota, Soresi, Ferrari and Minnes, 2006).

- Studies in the UK and the US have shown that the attitudes held by medical professionals may influence the quality of care provided to people with intellectual disability (Barker & Howells, 1990; Minihan, Dean and Lyons, 1993).

- Barriers to health care included communication difficulties and problems in obtaining patient histories. Other barriers included GPs' lack of training and experience, consultation time constraints, examination difficulties and continuity of care (Lennox, Diggens and Ugoni, 1997). [9]

9 526 GPs participated in a survey in Australia.

- In research investigating General Practitioners' educational needs in intellectual disability health, many GPs reported that they were inadequately trained in human relations and sexuality issues and these areas were also perceived as being of a poor standard. (Phillips et al., 2004). [10]

- Research has demonstrated that the practice of 'proxy' decision-making [11] was most prevalent in the context of decisions concerning women's reproductive health; negative attitudes towards the sexuality of people with intellectual disabilities had an impact on women's access to sexual health screening services (Keywood et al. 1999; Aunos and Feldman, 2002). Proxy decision-making occurred more frequently with those who lived in group residential services, thus supporting the contention by Wehmeyer & Bolding, writing in the US context, that choice and self-determination are hindered by institutionalised living environments (2001) or by living with family members.

- Keywood (2003) argues that a further obstacle to people's effective involvement in decisions about their care arises from the negative attitudes of some health and social care professionals towards people with intellectual disabilities. Keywood bases this argument on her own research (Keywood, 1999), which found that attitudinal barriers obstructed access to primary care.

- Canadian researchers found that young and better educated professionals (e.g. social workers) usually have more liberal attitudes towards the sexuality of people with intellectual disabilities than direct-care workers (Murray & Minnes 1994).

10 Survey comprising 252 GPs in Australia.

11 Keywood (1999) uses this term to refer to the kind of decision-making that involved relatives and paid carers making health care decisions on behalf of the participants in her study.

1.10 Structure of the review

The literature reviewed is presented under the following sections:

Section I.0: Introduction

Section 2.0: Contraception and consent to medical treatment

Section 3.0: Capacity to consent to sexual relationships

Section 4.0: Pregnancy risk and pregnancy experiences

Section 5.0: Parenting

Section 6.0: Discussion and conclusions

2.0 Contraception and consent to medical treatment

2.1 Introduction

This section will explore use of contraception and pregnancy risk for women with intellectual disability as well as discussing capacity issues and consent to medical treatment, with a particular focus on contraceptive treatment.

2.2 Contraceptive provision for women with intellectual disability

The fertility of women with learning disabilities has long been subject to control by others. McCarthy (1998) notes that there is a long history of eugenics-based practice in many countries, where the emphasis has been to prevent people with learning disabilities - along with so-other called 'unfit' people - from reproducing, either through sterilisation and/or through institutionalisation (Barker, 1983). Support for involuntary sterilisation derived from the belief that persons with intellectual disability were incapable of giving informed consent, and that the practice was necessary 'to avoid genetic transmission of mental retardation' (Carpenter, 1992). In relation to sexuality and reproductive health, historically decisions were based in public policy that was deeply influenced by discrimination and pervasive stereotypes. Meanwhile, Brown (1996) observes that, in the UK context, procedures such as the use of Depot Medroxyprogesterone Acetate (Depo-Provera) as a contraceptive and long-term use of the Pill are still widespread, despite the acknowledged health risks.

McCarthy (1998) notes that the reason for prescribing contraception to women with learning disabilities is not always a straightforward matter of preventing an unwanted pregnancy in a sexually active woman of child-bearing age. In her experience, a reason provided for many women was the existence of heavy or painful periods, which she suggests may be exaggerated by carers and staff in order to have a long-term strategy to avoid any possibility of pregnancy for all of the woman's reproductive life. She argues that the very long-term use of the Pill, and the ways in which intrauterine devices (IUDs) and Depot Medroxyprogesterone Acetate are used with women with learning disabilities, combined with a lack of attention to side-effects and after-effects, suggests that less importance

is placed on their health and future fertility than on other women's (McCarthy, 1999: 224).

Another reason proposed for prescribing contraception to women with intellectual disability is that such women, particularly those with severe intellectual disabilities, would be unable to practically manage their periods and/or that they would be very distressed by the sight of blood (Taylor & Carlson, 1993). McCarthy contends that there is actually very little evidence to support this point (1998). To protect a woman with intellectual disability from the sexually active men around her has also been used as a justification for prescribing contraception. Taylor and Carlson (1993) point out that prescribing contraception to a woman with learning disabilities thought to be at risk of sexual abuse in fact increases her vulnerability to abuse. As research has shown that perpetrators of abuse are more likely to be known to a woman with intellectual disability, the knowledge that a woman is using contraception provides protection in itself for a potential abuser, as he will know that pregnancy will not occur and therefore that there are fewer chances of his being caught and identified.

2.3 Research on use of contraception

Most research concerning the contraception of intellectually disabled women refers to the population attending a particular gynaecologist (Grover, 2002) or a clinic (Elkins, Gafford, Wilks, Muram and Golden, 1986; Chamberlain, Rauh and Passer, 1984). Mail surveys have also been conducted where directors in institutions have been asked to estimate how often the different contraceptive methods are used in their institutions (Gust et al., 2003).

2.3.1 Type of contraception used

The pattern of contraceptive use amongst women with intellectual disability differs widely from that of the non-disabled population. Longstanding research confirms that the Pill, Depot Medroxyprogesterone Acetate and IUDs are the only methods used by most women with learning disabilities, with barrier methods being reported as unheard of (Chamberlain et al., 1984: 449; McCarthy, 1998; Van der Merwe & Roux, 1987; Shet & Malpani, 1991). More recently,

Servais, Jacques, Leach et al.(2002) found in their study [12] that women with intellectual disabilities were more likely to be treated with sterilisation or Depot Medroxyprogesterone Acetate and less likely to be prescribed oral contraceptives.

Rodgers's study (2001) on the experience and management of menstruation for women with learning disabilities involved qualitative interviews/focus group with 21 women with mild to moderate learning disabilities from six locations in the South West of England. Her findings indicated that 11 of the 21 women had been given a medical intervention of some kind, including the contraceptive pill, Depot Medroxyprogesterone Acetate and hysterectomy. The women were not well informed about the nature of the interventions or possible side effects. For example, women taking the Pill did not know that it prevented pregnancy as well as making periods lighter and more regular.

The same study gathered the viewpoints of carers and health professionals (32 participants in total, comprising 11 family carers, 12 paid carers, four community learning disability nurses, and five general practitioners), who reported that medical interventions relating to menstruation appeared to be common, even routine. In one area many women were taking Norethisterone tablets to prevent menstruation.

It was felt that interventions were not always used with due care for the woman's overall well-being or health. Participants spoke of carers who had attempted to arrange sterilisation as well as hysterectomies for their daughters. These were perceived by carers as more difficult to arrange as they believed that gynaecologists might be reluctant to perform them, due to concerns about consent, the possible side-effects of the operation, and the woman not being able to comply with her post-operative care. Interventions were commonly seen as a way of 'protecting' women from unwanted pregnancy.

12 Servais et al.'s (2002) population based study involved a survey of 397 women with intellectual disability aged between 18 and 46 attending government funded facilities in Brussels and the province of Walloon Brabant in Belgium.

McCarthy (1999: 221), who carried out research with women with learning disabilities in England, notes that the reliance on low/no maintenance methods, such as those described above (Chamberlain et al., 1984), assumes that women with learning disabilities are incapable or unreliable when it comes to managing their own fertility. She suggests that as new forms of slow-release, long-acting contraception (such as implants) come onto the market one could expect these to be over-used as well (McCarthy and Thompson, 1998). It has also been argued that the use of long-lasting contraception like Depot Medroxyprogesterone Acetate reveals pressures to discourage the fertility of certain groups of women (Williams, 1992). IUDs are not generally the contraception of choice of younger women without learning disabilities, yet they are frequently used for women with learning disabilities (Chamberlain et al., 1984; Elkins et al., 1994).

McCarthy (1999:222) notes that the use of condoms is mentioned widely in the literature but this is almost exclusively in relation to HIV prevention. Use of the diaphragm: is almost entirely overlooked. McCarthy (1999) acknowledges the possible difficulties for a woman with learning disabilities in using a diaphragm: learning how to insert it properly, having to touch her genitals, inserting and removing it at the right times. The hurried nature of much of the sexual activity the women in her study reported to her would suggest that diaphragms would be impractical, as would the female condom for the same reasons (McCarthy, 1999: 223).

2.3.2 Factors influencing contraception usage

Research has shown that the living environment of women with intellectual disability is a determining factor in their use of contraception and the type of contraception used. Servais et al.'s (2002) population-based study involved a survey of 397 women with intellectual disability aged between 18 and 46 attending government-funded facilities in Brussels and the province of Walloon Brabant in Belgium. [13] Of these women, over 40 per cent did not use any contraceptive method, 22 per cent were sterilised, 18 per cent used an oral contraceptive agent, and

13 Findings from the survey indicated that 7% of the women were having or previously had had consenting sexual intercourse; 51% were not sexually active, and this information was not known for 41% of the women.

almost 18 per cent used Depot Medroxyprogesterone Acetate (DMPA). [14]

The researchers found that institutional factors played a major role in contraception usage amongst women with intellectual disability, factors such as whether the women were residing in an institution or at home with their parents, as well as the sexual relationship policy and contraception policy of the institution. The following factors were associated with an increased probability of using contraception:

- Residing in an institution
- Living in an institution where contraception is required or advised
- Living in an institution where sexual intercourse is not prohibited
- Having a milder disability.

Servais et al. (2002) comment on the low influence of personal or medical factors in the women's use of contraception and argued that medical factors should be given more consideration when decisions about contraception are being made. They assert that contraception for sub-groups of women with intellectual disability should be more comprehensively managed, taking into account medical factors and the heterogeneity amongst women with intellectual disability. Contraceptive choices, they argue, should not be exclusively influenced by environmental factors.

Other findings from Servais et al.'s research included:

- Previous sexual intercourse and involvement in an affective relationship were strongly associated with the level of disability.

- Women with severe intellectual disability had increased usage of Depot Medroxyprogesterone Acetate.

14 The authors note that these figures differed widely from the general Belgian population. Women with ID were using contraception less frequently (60% versus 68%), their contraceptive method was less likely to be an oral contraceptive agent (18% versus 46%), and more often sterilisation (22% versus 7%) or DMPA (17% versus <2%) (Servais et al., 2002).

- Contraception in women with mild intellectual disability was less dependent on the factors associated with contraception amongst women with moderate or severe intellectual disability. The authors suggest that the reasons for this may be women with mild intellectual disability's greater decision-making capacity, thereby making them less dependent on the choices of the facility.

- Existence of a sex education programme seemed to be associated with a decreasing probability of Depot Medroxyprogesterone Acetate usage, especially for women with moderate intellectual disability.

Some research findings highlight how important sex education training and programmes are for women with intellectual disability. Cheng and Udry's research (2005) examined a longitudinal survey of adolescent health in the US, identifying 422 adolescents with low cognitive abilities. [15]

Findings in relation to birth control included:

- Mental ability was positively associated with birth control: the higher the mental ability the greater the likelihood of using birth control; for example, amongst sexually experienced girls only 38 percent of those with low cognitive abilities used birth control for their first experience of sex, and 39 percent for their most recent sexual experience, compared with 63 per cent and 65 per cent for girls with average intelligence.

- Almost half of the girls with low cognitive abilities consistently did not use any protection during sex; results showed that the likelihood of these girls not using any birth control for their first or most recent sexual experience was five times greater that for girls with average intelligence.

15 Cognitive abilities were measured using Add Health Picture Vocabulary Test (AHPVT); those respondents who scored below 70 comprised their research sample.

Research carried out in Northern Ireland with 62 individuals with learning disabilities sought to gather their knowledge, personal experience and values and attitudes on a number of matters relating to sexuality and relationships including menstruation, masturbation, intimacy, sex and the law, reproduction, and sexual health (Simpson, Lafferty and McConkey, 2006). Thirty-nine of the participants were aged between 13 and 25, and 23 participants were aged between 26 and 40.

Interviewees' knowledge of contraception and sexually transmitted infections was generally lower than the other areas of knowledge. For example, only 50 per cent knew of ways to prevent pregnancy – the condom and the contraceptive pill were the most common responses. Women tended to know more about contraception than men and there were also significant differences with regard to knowledge about the intrauterine device (IUD) and the contraceptive injection. Meanwhile, 18 per cent knew the meaning of birth control/contraception.

2.3.3 Decision-making and contraception

Historically, for the majority of women with intellectual disability, decisions about contraceptive treatment were made by other people, and they were not consulted. The 15 women with learning disabilities in McCarthy's (1998) study who had ever used contraception were asked who had decided whether they should have it and which contraception to use. Seven of the women said doctors had decided, two said their parents had decided (one of these women appeared not to even know she had an IUD in situ), two said staff in learning disability services had decided and three did not know or could not remember. Only one woman said she had made the decision for herself, which McCarthy describes as a shocking fact, given the high levels of intellectual ability in the group (McCarthy, 1998: 568).

McCarthy argues that it is undeniably the case that some women with learning disabilities would find making decisions about which type of contraception to use very difficult and would also find it hard or impossible to manage the practicalities of some methods. At the same time, she asserts that many women with learning disabilities, (including women in her own study) are not given sufficient or appropriate information and support to make those choices themselves (McCarthy, 1998).

Wehmeyer and Bolding's research (2001) in the US with 31 adults with intellectual disability contributed to evidence that the self-determination of individuals with intellectual disability is limited by congregate living, which limits opportunities for choice and decision-making. Keywood (1999) notes from her research that proxy decision-making [16] is highly prevalent in decisions relating to the reproductive health of women with disabilities in which negative attitudes about the sexuality of people with intellectual disability influence a woman's access to sexual health services (see also Aunos and Feldman, 2002).

2.4 Legal framework governing capacity to consent

The discussion around the use of contraception by people with intellectual disability involves the issue of whether or not a person with intellectual disability has the capacity to give informed consent to medical treatment, including contraceptive treatment. The literature describes how different jurisdictions legislate for substitute decision-making where people with intellectual disabilities are deemed to lack capacity. Capacity legislation also provides guidance on how capacity or lack of capacity is to be defined and assessed.

Capacity is defined in proposed Irish legislation [17] as 'the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made.' A person lacks the capacity to make a decision if she/he is unable to:

- Understand the information relevant to the decision;
- Retain that information;
- Use or weigh that information as part of the process of making the decision;
- Communicate her/his decision (whether by talking, using sign language or any other means) or, if the decision requires the act of a third party to be implemented, to communicate by any means with that third party. [18]

16 Keywood (1999) uses this term to refer to the kind of decision-making that occurred on behalf of the participants in her study, involving relatives and paid carers making their health care decisions.

17 Head 2(1) of the Scheme of Mental Capacity Bill 2008 and Section 7 of the Mental Capacity and Guardianship Private Members' Bill 2008.

18 Any question as to whether a person has capacity is to be decided on the balance

Some women with intellectual disability are deemed to have the necessary capacity to consent to treatment, others are deemed as lacking capacity to consent to treatment. It is the responsibility of the relevant medical practitioner to ensure that a person has capacity to make a healthcare decision (LRC, 2005). According to the Law Reform Commission the area of assessment of capacity to make healthcare decisions is fraught with uncertainty (LRC 2006: 31). Issues surrounding women's capacity to consent to medical treatment and how capacity is assessed are discussed in Section 2.8.

Where a woman is deemed to be lacking the capacity to consent to treatment legal provisions come into force to allow others to make decisions on behalf of the woman.

2.4.1 Legal framework governing capacity in Ireland

General principles concerning capacity

In Ireland, under the current law, there is a presumption that once a person reaches 18 they have the legal capacity required to make decisions affecting their lives. The equality guarantee under Article 40.1 permits the State in its laws to have regard to differences in capacity provided that it does not create invidious discrimination. There are no generally applicable definitions of capacity at common law or in statute. The major limitation on capacity relates to minors. Section 2 of the Age of Majority Act, 1985 provides that persons under 18 who have not married are minors in law and generally do not have legal capacity. Parents are generally the joint legal guardian and while the child is under 18 have the legal capacity to make decisions affecting the child's welfare.

Wards of court system

Currently in Ireland, the Wards of Court system, which is centred in the High Court, is the primary mechanism for managing the affairs of

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of probabilities. In determining what is in a person's best interest, Head 3 of the Scheme of the Mental Capacity and Guardianship Bill 2008 provides that the person must, as far as is reasonably practicable, be permitted to participate, or to improve his/her ability to participate, as fully as possible in any act done for him/her and any decision affecting him/her.

persons who lack decision-making capacity. [19] Where a person is considered incapable of managing his/her affairs, an application can be made to the High Court to make that person a ward of court. The Supreme Court has pointed out that the impact of being made a ward of court is monumental. [20]

2.4.2 Legislative reform in Ireland – Scheme of Mental Capacity Bill 2008

New legislation has been proposed, which aims to reform the law concerning capacity, in so far as it applies to adults, and to introduce a modern framework governing decision-making on behalf of persons who lack capacity. This legislation is the Scheme of Mental Capacity Bill 2008. [21] Another Bill covering legislation in this area, a Private Members' Bill entitled Mental Capacity and Guardianship Bill 2008 (hereafter referred to as 'The Private Members' Bill'), was introduced in the Senate in February 2008. [22]

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19 An enduring power of Attorney is a legal mechanism established by the Powers of Attorney Act 1996 for granting certain decision-making power to a nominated attorney in the event that the person loses capacity.

20 When a person is made a Ward of Court, the Court is vested with jurisdiction over all matters relating to the personal estate of the ward (Re A Ward of Court (No 2) (1996) 2IR 79). The result of this is that a person who has been made a Ward of Court loses the right to make any decisions about their person and property. Although the court will have regard to the views of the ward's committee (in effect guardian) and family members, the Court will make conditions based on the criterion of the 'best interests' of the ward but generally no attempt is made to consult the ward in relation to the decision.

21 Proposals for the drafting of the Scheme of Mental Capacity Bill 2008 were approved by Government on 3 September 2008. Publication of the Bill was expected in the Spring of 2009; however, it seems likely that this will not occur until some time in 2010. The Scheme of Mental Capacity Bill 2008 is based on the Law Reform Commission's recommendations in this area as set out in their report, Vulnerable Adults and the Law (LRC, 2006). This report - LRC 83-2006 - contains a Draft Scheme of Mental Capacity and Guardianship Bill (hereafter referred to as the Law Reform Commission Bill), which is quite similar to but not identical to the scheme of the Mental Capacity Bill 2008.

22 A previous Private Members' Bill entitled the Mental Capacity and Guardianship Bill 2007 (Bill no. 12 of 2007) had been introduced in the Senate, but fell with the dissolution of the Oireachtas.

It is envisaged that the provisions in relation to consent to medical treatment as set down in the Scheme of Mental Capacity Bill, 2008 (discussed below) will apply to contraceptive treatment and to other medical treatments/interventions in relation to the pregnancy experiences of women with intellectual disabilities. Namhi [23] (2003), in their report on legal capacity and decision-making, stated that contraception should be subject to the same rules that apply for medical treatments in general.

The aim of the Scheme of Mental Capacity Bill 2008 is to give effect to the Hague Convention on the International Protection of Adults [24] and the UN Convention on the Rights of Persons with Disabilities [25].

2.5 Scheme of Mental Capacity Bill, 2008

This section will examine the provisions of the Scheme of Mental Capacity Bill, 2008 and the issues surrounding capacity assessment and proxy decision-making arising from the Bill.
The Scheme of Mental Capacity Bill includes sections on the following areas:

- Guiding principles
- Definition and presumption of capacity
- Best interests
- Power to make decisions and appoint personal guardians
- Informal decision-making

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23 Namhi are now known as Inclusion Ireland, which is the National Association for People with an Intellectual Disability.

24 Ireland is a signatory to the Hague Convention, which came into force in January 2009. The Convention is designed to improve the protection in international situations of adults who, by reason of an impairment or insufficiency in their personal faculties, are not able to safeguard their own interests.

25 The UN Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly in 2006. It is a major Human Rights Convention which aims to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities.

- Consent and capacity in specific contexts
- Structures
- The Office of Public Guardian
- Enduring powers of attorney.

2.5.1 Guiding principles

The Scheme of Mental Capacity Bill contains a number of guiding principles to assist both the court and persons making a decision on behalf of an adult who lacks capacity: [26]

- Presumption of capacity: In Irish law, as in many other jurisdictions, there is a presumption that adults have capacity, which can be removed only if there is clear evidence that the person lacks the necessary capacity.

- No intervention is to take place unless it is necessary, having regard to the needs and individual circumstances of the person, including whether the person is likely to increase or regain capacity.

- A person will not be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.

- A person is not to be treated as unable to make a decision merely because she/he makes an unwise decision.
- Any act done or decision made under the Bill must be done or made in the way which is least restrictive of the person's rights and freedom of action.

- Due regard must be given to the need to respect the right of a person to her/his dignity, bodily integrity, privacy and autonomy.

26 The Private Members' Bill also contains guiding principles at Section 4. The presumption of capacity is not set out as a guiding principle in The Private Members' Bill but is contained in Section 6.

- Account must be taken of a person's past and present wishes, where ascertainable.

- Account must be taken of the views of any person with an interest in the welfare of a person who lacks capacity, where these views have been made known. [27] The Bill does not specify a hierarchy of authority in this regard. It would therefore appear that a health professional would need to take into account the views of all of these people when considering treatment to be provided. However, a health professional's overriding duty is still to act in the patients' best interests. [28]

- Any act which is done or any decision made under this Bill for or on behalf of a person who lacks capacity must be done or made in her/his best interests.

2.5.2 Approach to decision-making

Protection from liability for those providing health care and treatment

Head 16 of the Scheme of Mental Capacity Bill [29] provides protection from liability in certain circumstances for informal decision-making in relation to a person who performs an act in connection with the personal care, healthcare or treatment of another person whose decision-making capacity is in doubt. Before a medical practitioner (or another person) performs any act in connection with the personal care, health care or treatment of another person whose decision-making capacity is in doubt, she/he must have regard to the general principles and comply with the following requirements:

1. Before doing the act, take reasonable steps to establish whether the person lacks capacity in relation to the matter in question.

27 Section 4 of the Private Members' Bill specifies who should be consulted, including relatives, the primary carer, the person with whom he or she resides, any person named as someone who should be consulted.

28 Elaine Healy, Beauchamps Solicitors, information accessed December 2008 at http://www.imt.ie/opinion/2008/09/mental_capacity_bill_2008.html

29 There are equivalent provisions in Section 8 of the Private Members' Bill.

2. When doing the act, reasonably believe that the other person lacks capacity in relation to the matter in question, and it is in the other person's best interests that the act be done.

The Bill gives medical practitioners (and other caregivers) immunity from liability if they follow the steps above when treating patients. There is also specific protection afforded in Head 17(3) in relation to the provision of life-sustaining treatment, or the doing of any act which he or she reasonably believes to be necessary to prevent a serious deterioration in a person's condition. [30]

2.5.3 Guardianship

Where a person has been found to lack capacity, a personal guardian can be appointed by the High Court or the Circuit Court to make decisions, including decisions concerning her/his healthcare. Under the Scheme of Mental Capacity Bill 2008, there is provision for informal decision-making for health care and treatment, subject to restrictions. The powers of a Personal Guardian in relation to personal welfare decisions extends to, 'giving or refusing consent to the carrying out or continuation of a treatment by a person providing healthcare for the person who lacks capacity'. [31] Similarly, Head 48 of the Scheme of the Bill provides that the scope of authority of an attorney under enduring power in relation to personal welfare decisions (which have to be made in the best interest of the donor) includes a decision on health care, where the donor lacks - or the attorney reasonably believes that the donor lacks - capacity. [32] The Law Reform Commission's report (LRC, 2006:34) considered this issue, suggesting that a Personal Guardian may have power to make day-to-day decisions, including the giving of consent to any necessary routine or minor medical treatment.

Decisions on certain major procedures would have to comply with the procedures as set down in the Scheme of Mental Capacity Bill, 2008.

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30 Head 11 (3) of the Scheme of Mental Capacity Bill and Section 23 of the Private Members' Bill provides that a Personal Guardian may not refuse to the carrying out or continuation of life-sustaining treatment.

31 Head 7(1)(g) of the Scheme of Mental Capacity Bill 2008.

32 Currently an enduring power of attorney can apply to property, financial, business and personal care decisions, but not healthcare decisions.

Decisions on treatments such as non-therapeutic sterilisation can only be made by the High Court, as set down in the Bill. [33]

The Bill will also establish an independent Office of Public Guardian to supervise persons appointed by the courts to perform guardianship or decision-making functions on behalf of incapacitated persons. In situations where there is no person willing or able to act as a personal guardian, the Office will act as a guardian of last resort.

2.5.4 Codes of practice

The Scheme of Mental Capacity Bill 2008 provides that the Public Guardian shall prepare and issue codes of practice for the guidance of persons - including healthcare professionals - on, inter alia:

- assessing whether a person has capacity, and
- acting in connection with the care or treatment of another person in their informal decision-making
- the circumstances in which urgent treatment may be carried out without the consent of an adult patient who lacks capacity and what type of treatment may be provided if it is likely that the person will imminently recover capacity. [34]

2.5.5 Capacity in specific contexts

The Scheme of Mental Capacity Bill 2008 does not apply to the following contexts:

- capacity and consent to marriage or civil partnership
- consent to a judicial separation, a divorce or a dissolution of a civil partnership
- consent to a child being placed for adoption
- consent to the making of an adoption order
- consent to have sexual relations
- voting at an election or at a referendum
- acting as a member of a jury.

33 Head 21 of the Scheme of Mental Capacity Bill and Section 20 of the Private Members' Bill.

34 Head 39 of the Scheme of Mental Capacity Bill and Section 27 of the Private Members' Bill.

2.6 Critique of the Law Reform Commission Draft Scheme of Mental Capacity and Guardianship Bill 2008 [35]

Donnelly (2008) critiqued the Law Reform Commission's Draft Scheme of Mental Capacity and Guardianship Bill and highlighted the following concerns:

- The proposed definition of capacity is too open-ended and lacks a degree of precision. The approach advocated by the Law Reform Commission leaves decision-makers with very little guidance in developing and applying the test for capacity in individual cases (Donnelly, 2008: p147).

- A more appropriate definition, she argues, would impose positive obligations on assessors to facilitate the development of capacity and to deliver information in a manner appropriate to the needs of the person whose capacity is assessed. Such an approach would go some way towards ensuring that, to the maximum degree possible, decision-making power remains with the person herself and is not lost because of a lack of capacity when such a finding can be avoided. This area of concern has subsequently been addressed under the Guiding Principles (Head 1 (c)) and under the Definition of Capacity (Head 2 (3)) of the Scheme of Mental Capacity Bill 2008. [36]

- There is no provision relating to advocacy in the proposed structure, either at the individual level through the appointment of personal advocates or at a policy level through the inclusion of an advocacy requirement among the functions of the Office of the Public Guardian. Special efforts need to be made to provide meaningful protection for the rights of people lacking capacity. (It is noteworthy that Head 15 of the Scheme of Mental Capacity Bill

35 The Law Reform Commission Report on Vulnerable Adults and the Law, LRC 83-2006, p169

36 Head 1 (c) states that 'a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.' Head 2 (3) states that 'a person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (using simple language, visual aids or any other means).'

2008 provides for a scheme to provide legal representation where required.)

- In the context of informal decision-making and the provision of protection from liability for those providing healthcare and treatment, Donnelly (2008) proposes that there should be a requirement to obtain the consent of the 'person responsible' for the person lacking capacity. The inclusion of such a special provision requiring consent to medical treatment, even in relation to 'routine' procedures, provides a better degree of protection for people lacking capacity. She argues that while most medical professionals undoubtedly include the family members or carers of a person lacking capacity in treatment decisions, the legislation should include a specific provision requiring them to do so. Part 5 of the New South Wales Guardianship Act 1987 contains a requirement in relation to medical and dental treatment, whereby the consent of the 'person responsible' for the person lacking capacity is required. [37]

- A requirement that the person lacking capacity should be consulted regarding the choice of personal guardian should be included in the legislation.

2.7 Legal capacity in other jurisdictions

Different jurisdictions have their own legal process for substitute decision-making in situations where a person with an intellectual disability lacks the capacity to consent.

2.7.1 Legal capacity in England and Wales

An adult client with capacity (over 18) has the right to refuse any medical treatment, whatever the consequences, unless it is compulsory treatment for a mental disorder (for someone sectioned under the Mental Health Act). The Mental Capacity Act, 2005, provides a statutory framework for substitute decision-making for those who lack capacity. It states that a person lacks mental capacity if at the material time he

37 Part 4 of the Guardianship and Administration Act 1986 (Victoria) and part 5 of the Adults with Incapacity (Scotland) Act, 2000.

or she is unable to make a decision for him or herself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain (Section 2(1)).

Functional test of capacity

The Mental Capacity Act goes on to say (Section 3) that a person is unable to make a decision due to a lack of mental capacity, when he is unable to:

- Understand the information relevant to the decision, (including understanding the likely consequences of making, or not making the decision - Section 3(4))
- Retain that information
- Use or weigh that information as part of the process of making the decision
- Communicate his/her decision (whether by talking, using sign language or any other means).

The key point about this definition of capacity, as well as similar definitions in other jurisdictions, is that capacity is function specific. A person's capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made. Thus, a person may be competent to make certain decisions but not others.

Many of the provisions of the Mental Capacity Act, 2005, are based on existing common-law provisions. The Act clarifies and improves upon these principles and builds on current good practice, which is based on the principles. [38]

38 Para 1.6 of the Mental Capacity Act, Code of Practice.

There are five key principles set down in the Act:

Presumption of capacity:

- The starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity.
- A person is not to be treated as unable to make a decision unless all practical steps to help him or her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he or she makes an unwise decision.

Best interests:

- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made in his best interests.

Least restrictive option:

- Before the act is done or the decision is made, regard must be taken as to whether the purpose for which it is needed can be as effectively achieved in a way that is least restrictive to a person's rights and freedom of action.

Protection from liability for those providing health care and treatment
Section 5 of the Mental Capacity Act, 2005, allows carers, healthcare and social care staff to carry out certain tasks without fear of liability, subject to certain conditions. These tasks involve the personal care, healthcare or treatment of people who lack capacity to consent to them. The aim is to give legal backing for acts that need to be carried out in the best interests of the person who lacks capacity to consent. [39] The actions that might be covered under Section 5 only receive protection from liability if before doing the Act the person takes reasonable steps to establish whether the person lacks capacity and if he reasonably believes that the person lacks capacity to give permission for the action and that it will be in the person's best interest.

39 The provisions of S. 5 are based on the common law 'doctrine of necessity', as set out in Re F (Mental Patient: Sterilisation) [1990] 2 AC 1.

Good practice provisions of the Mental Capacity Act, 2005, England and Wales

Good practice in relation to the provisions of the Mental Capacity Act, 2005 include:

Functional approach

The Mental Capacity Act adopts a functional approach based on establishing the extent to which the person's understanding, knowledge, skills and abilities meet the demands of the task involved in making that particular decision within a given legal context (Grisso, 1986). Any assessment of a person's capacity must be 'decision-specific', meaning that it must be about the particular decision that has to be made at a particular time and is not about a range of decisions; capacity is decision and time specific, rather than global or permanent. Under the functional approach to capacity, a new assessment of capacity is required for each new decision or task (Donnelly, 2007). Just because a person may lack capacity to make a decision on one occasion does not mean that they will never have capacity to make a decision in the future about a different matter; if someone cannot make complex decisions, this does not mean that they cannot make simple decisions.

The implication is that before making any declaration of incapacity, consideration needs to be given as to whether it would be possible either to improve the person's relevant functional abilities (for example, by ensuring that he/she is offered education or additional support) and/or to simplify or otherwise amend the situation to improve the person's capacity (Murphy and Clare, 2003). According to Myron, Gillespie, Swift and Williamson (2008) a functional approach has been increasingly preferred when assessing capacity and recommended to professionals such as medical practitioners and psychologists in their professional guidance. [40]

40 For example, Assessment of mental capacity, British Medical Association/Law Society (2004), Assessment of Capacity in Adults: Interim Guidance for Psychologists, The British Psychological Society (2006), see also Suto, Clare & Holland (2002).

Legal duty to consult with others

The Act places a duty on the decision-maker to consult other people close to a person who lacks capacity, where practical and appropriate, on decisions affecting the person and what might be in the person's best interests (Bartlett, 2008). In particular, under Section 4 (7) the decision-maker has a duty to take into account the views of people including: anyone the person has previously named as someone they want to be consulted; anyone involved in caring for the person; anyone interested in their welfare (for example, family carers, other close relatives, or an advocate already working with the person) (Bartlett, 2008).

Recognition of the contingent nature of incapacity

Recognises the contingent nature of incapacity and requires assessors to go beyond simply assessing capacity and to take steps to develop capacity. Section 1 (3) states that a person is not to be treated as unable to make a decision unless 'all practicable steps to help the person have been taken without success'. Section 3 (2) provides that a person is not to be regarded as unable to understand relevant information if the person 'is able to understand an explanation of it given to him in a way that is appropriate to his circumstances'. (There are equivalent provisions in the Scheme of Mental Capacity Bill 2008.) Thus, according to Donnelly (2008), the Mental Capacity Act 2005 requires steps to be taken and imports a right to comprehensible information into the statutory definition of capacity.

Assessment of capacity

Under the Mental Capacity Act 2005, a person is required to make an assessment of capacity before carrying out any care or treatment. The more serious the decision, the more formal the assessment will need to be. (See Chapter 4 of the Mental Capacity Code of Practice.)

Best interests standard

The Act requires people to follow certain steps to help them work out whether a particular act or decision is in a person's best interests. Where the person who acts or makes the decision has followed the steps to establish whether a person has capacity and done everything they

reasonably can to work out what someone's best interests are the law should protect them.

These steps include but are not limited to:

- encouraging participation
- identifying all relevant circumstances
- finding out the person's views
- avoiding discrimination by not making assumptions based on a person's age, appearance, condition or behaviour
- assessing whether the person might regain capacity
- consulting others
- avoiding restricting the person's rights
- taking all these factors into account.

(Chapter 5 of the Code of Practice includes guidance on how to carry out these steps.)

Safeguards

Safeguards are provided in the legislation, i.e. it cannot be decided that someone lacks capacity based on their age, appearance, condition or behaviour alone.

Advocacy structure

The Act provides for an Independent Mental Capacity Advocate (IMCA) service, the aim of which is to provide independent safeguards for people who lack capacity to make certain important decisions about serious medical treatment and changes of accommodation and, at the time such decisions need to be made, have no family or friends that it would be appropriate to consult. An IMCA may be consulted to support someone who lacks capacity to make decisions concerning care reviews and adult protection cases.

2.7.2 Legal capacity in Canada

In Ontario, Canada, the relevant statute in this area is the Health Care Consent Act 1996, which covers treatment, admission into a long-term facility, and decisions about personal assistance services. Mental Capacity is a legal construct and means the ability to firstly 'understand'

information that is relevant to the decision and then 'appreciate 'reasonably foreseeable consequences'. The Health Care Consent Act, Section. 4 (1) defines capacity as follows:

> A person is capable with respect to a treatment ... if the person is able to understand the information that is relevant to making a decision about the treatment ... and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

'Treatment' is defined (subject to significant exclusions) as anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan. Section 11 defines the elements required for consent to treatment as:

1. must relate to the treatment
2. must be informed
3. must be given voluntarily
4. must not have been obtained though misrepresentation or fraud.

Section 11 (2) states that informed consent requires the person to have received information that a reasonable person in the same circumstances would require about:

1. The nature of the treatment
2. The expected benefits of the treatment
3. The material risks of the treatment
4. The material side-effects of the treatment
5. Alternative courses of action
6. The likely consequences of not having the treatment.

Section 11 (2) also states that informed consent requires that the person has received responses to his or her requests for additional information about those matters listed above.

The Health Care Consent Act 1996 also contains the principle of 'presumption of capacity', with an exception in the case where a person

has reasonable grounds to believe the other person is incapable in respect to treatment. A functional approach to capacity assessment is also adopted in this legislation in that a person may be capable in respect of some treatments and incapable in respect of others, and a person may be incapable with respect to treatment at one time and capable at another.

The Ontario Capacity Assessment Office identified key tenets that represent the ethical foundation of capacity assessment in the context of the Substitute Decisions Act 1992 [41] (Ontario Ministry of the Attorney General, 2005). These include:

- The right to self-determination.
- Presumption of capacity.
- 'Decisional' capacity: The presence of mental illness or a significant cognitive deficit does not necessarily preclude rational decision-making in all aspects of a person's life. The emphasis is on the quality of the decision-making process, not the actual course of action in which a person engages. (This requires exploration of the particular line of reasoning employed by the person in making decisions, and whether or not those decisions are consistent with a personal belief system, known values and reality.)
- Incapacity is domain specific: The notion of global incapacity is rejected; capacity may be limited only with respect to certain decisions or classes of decisions. The advantages of this approach are firstly that it ensures that the person's rights will not be removed in areas where he/she is still able to manage and secondly guardianship orders can be tailor-made to confer powers only where they are needed and clear benefits derive.
- Guardianship as a last resort: Guardianship as a legal option should only be used as a last resort when existing supports

41 Provides for property/financial decisions, powers of attorney, as well as personal care decisions.

become inadequate or a legally authorised intervention would bring substantial benefits to the incapable person.

2.7.3 Legal capacity in the United States

In the United States the determination of capacity to make decisions regarding reproductive issues has been recommended to require at a minimum the ability to:

- understand the therapy or procedure in question (contraceptive method or sterilisation)
- deliberate about the risks and benefits of each (including the risk of pregnancy)
- consider alternatives
- make a decision on the basis of these considerations.

(Beauchamp & Childress, 2001)

The American Academy of Pediatrics' Committee on Bioethics discusses the steps that should be taken when considering sterilisation in particular and in relation to contraceptive methods more generally:

- The first step in decisions about contraception generally involves assessing the individual's capacity to decide matters specifically concerning reproduction.

- Such assessments should be made with the help of professionals skilled and experienced in evaluating the capabilities of persons with disabilities.

- Health professionals should involve their patients who have an intellectual disability in decisions about reproduction and should advocate for the least permanent and intrusive method of contraception with the lowest risk for the patient.

- The assessment should focus on the individual's ability to understand appropriately presented information about the possibility of reproducing, the consequences of procreation, and the benefits and risks of, and alternatives to, pregnancy and childbirth (American Academy of Pediatrics, 1999).

They point out that evaluating a person's ability to provide consent may be quite complex in actual practice. Ultimately, they note that capacity is a legal attribute, and legal standards for determination of capacity vary greatly. In the U.S. some states require judicial review with representation of the individual by an attorney and guardian ad litem [42], and a competency evaluation (American Academy of Pediatrics, 1999). In those states without such a legal requirement, in the case of an elective procedure with permanent consequences, the American Academy of Pediatrics recommends that all possible efforts should be made to conduct the determination of competence fairly. Applebaum & Grisso (1988) point to the importance of considering language and cultural background, quality of information provided to the person (clarity, completeness, lack of bias), and fluctuations in a person's comprehension resulting from, for example, various stressors and medications.

A person who can demonstrate adequate capacity to comprehend the facts and associated concepts and express choices about these matters can provide informed consent or refusal for contraception, including sterilisation.

2.8 Capacity to make healthcare decisions

2.8.1 Informed consent

Many women with intellectual disability can give informed consent, and some cannot. At common law the giving of informed consent is a prerequisite to the carrying out of medical treatment. [43] An element of the concept of informed consent at common law is the requirement that the patient has the necessary capacity to decide whether or not to have the proposed medical treatment (LRC, 2006: 81). There is no generally

42 Guardian at law.

43 Indeed the doctrine of informed consent is part of a medical practitioner's duty of care under the tort of negligence and has been judicially recognised as an aspect of the constitutional right of privacy which ensures the dignity and freedom of the individual -Re A Ward of Court (no 2) 91996) 2 IR,79,163. The requirement of consent to medical treatment is an aspect of the constitutional right to bodily integrity and may involve article 8 of the ECHR. See also the Council of Europe's Convention on Human Rights and Biomedicine. Oviedo,4 IV 1997.

applicable statutory definition of informed consent in Irish law. However, Section 56 of the Mental Health Act 2001 provides a statutory definition of consent in the context of treatment of a 'mental disorder' of a patient covered by the legislation:

'Consent', in relation to a patient, means consent obtained freely without threats or inducement, where:

a. The consultant psychiatrist responsible for the care and treatment of the patient is satisfied that the patient is capable of understanding the nature, purpose and likely effects of the proposed treatment; and
b. The consultant psychiatrist has given the patient adequate information, in a form and language that the patient can understand, on the nature, purpose and likely effects of the proposed treatment.

(Mental Health Act, 2001)

The Law Reform Commission's Consultation Paper on Capacity (LRC, 2005:168) states that, in general terms, informed consent essentially requires that the following elements be satisfied:

- Prior disclosure of sufficient relevant information by the medical practitioner to the patient to enable an informed decision to be made about the treatment proposed.

- The patient has the necessary capacity at the time to decide whether or not to consent to the proposed treatment.

- The context allows the patient to voluntarily make a decision as to whether to consent to or to decline the proposed treatment.

In essence, people are entitled to receive information that is appropriate, relevant and through such channels that enable them to make a decision about their healthcare.

2.8.2 Assessment of capacity

It is the responsibility of the relevant medical practitioner to ensure that a person has capacity to make a healthcare decision (LRC, 2005). According to the Law Reform Commission the area of assessment of capacity to make healthcare decisions is fraught with uncertainty (2006: 31). Under current arrangements, health professionals have to exercise personal judgement in assessing capacity and determining how to proceed if an adult is assessed as lacking the capacity to make a healthcare decision. In non-emergency situations (where the doctrine of necessity is not applicable), healthcare professionals find themselves in a difficult position (LRC, 2006).

The only professional guidance available for Irish medical professionals is found in the Medical Council's 'A Guide to Ethical Conduct and Behaviour' (The Medical Council Ireland, 2004: 31), which states:

> Informed consent can only be obtained by a doctor who has sufficient training and experience to be able to explain the intervention, the risks and benefits and the alternatives. In obtaining this consent the doctor must satisfy himself/herself that the patient understands what is involved by explaining in appropriate terminology. A competent adult patient has the right to refuse treatment. While the decision must be respected, the assessment of competence and the discussion on consent should be carried out in conjunction with a senior colleague.

According to this guide, if a person with a disability lacks the capacity to give consent, a consultation involving parents/guardians and appropriate carers should occur (The Medical Council, Ireland, 2004: 11).

The Law Reform Commission (LRC) has recognised that practices have now become established such as seeking a signature on a consent form, which has no standing in law. The Law Reform Commission asserts that there is a need for guidance for medical practitioners in relation to:

- How capacity to make healthcare decisions should be assessed

- What action the law requires if a person is judged not to have the capacity to make a healthcare decision (LRC, 2006: 32).

In this regard, Sections 27(2) and 27(3) of the Mental Capacity and Guardianship Bill, 2008 [44] (Private Members' Bill) provide for the appointment of a 'Working Group on Capacity to make Healthcare Decisions', a body which would be tasked to formulate a code of practice on assessment of capacity. (The Scheme of Mental Capacity Bill 2008 does not provide for a working group on capacity; however, it does require consultation with relevant expert groups before preparing a code (Head 39(3)).

In the United Kingdom, there is detailed guidance available to medical professionals and lawyers, which was published in 2004 before the implementation of the Mental Capacity Act, 2005. [45] The guidance examines the key roles doctors and lawyers play in the assessment of capacity, and covers legal principles, the specific legal tests for capacity and practical guidelines for doctors and lawyers. (In the UK, the Mental Capacity Act 2005 Code of Practice provides detailed guidance on the assessment of capacity.)

Research findings in England have demonstrated that the knowledge base on assessment of capacity issues amongst medical professionals was inadequate. For example, in a study of 129 health professionals (including 35 GPs, 31 psychiatrists, 29 old-age psychiatrists, and 34 final-year medical students) correct answers on capacity to consent to or refuse medical treatment were given by only 20 per cent of the GPs, and 15 per cent of respondents believed that they could forcibly treat an individual who refused (Jackson and Warner, 2002; see also Carlson, Hames, English and Wills, 2004). Donnelly (2007) points out that given the lack of guidance for Irish doctors, there is likely to be an even greater level of confusion in this jurisdiction.

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44 This is a Private Members' Bill, which reproduces the suggested draft Bill in the Law Reform Commission report. Subsequent to this, the Department for Justice Equality and Law Reform has produced draft Heads of its own Bill (Scheme of Mental Capacity Bill 2008.)

45 British Medical Association and the Law Society (2004) - Assessment of Mental Capacity. Guidance for Doctors and Lawyers.

In the absence of explicit assessment guidelines, there is a danger that incapacity might be inferred solely on the grounds that the individual has a disabling medical or psychiatric condition. The Ontario Ministry of the Attorney General (2005) states that the Substitute Decisions Act 1992 created the opportunity for the introduction of a standard assessment protocol, which would reduce bias and introduce consistency in the way that mental capacity assessments are conducted (Ontario Ministry of the Attorney General, 2005.) [46]

The Department of Health in the UK has published the 'Good Practice in Consent Implementation Guide: consent to examination or treatment' (DH, 2001). The good practice in consent implementation guide contains a model consent policy and four consent forms, together with an accompanying information leaflet. The model documentation was developed as part of the Department of Health's 'Good Practice in Consent' initiative, with the aim of assisting National Health Service (NHS) organisations to promote good practice in the way patients are asked to give their consent to treatment, care or research.

Four consent forms were developed; the fourth one is of particular relevance to staff working with people with learning disabilities (see Appendix A). It provides guidance on how an individual practitioner might assess a person's capacity and then decide, with support from others, whether it is in the person's best interests to carry out the investigation or treatment. (See also the Mental Capacity Act 2005, Code of Practice for detailed guidance.)

2.8.3 Supporting decision-making

Hobden & Mills (2008) emphasise the need to properly assess the capacity of the individual in question to make his/her decision and to recognise that people with intellectual disabilities may have the capacity to both give and withhold consent to medical or surgical treatment. They note that the competent individual has the right to make the wrong decision, even for reasons that may be irrational or non-existent to health professionals (Hobden & Mills, 2008). The mere presence of emotional responses such as that of panic or irrationality does not in

46 Guidelines for Conducting Assessment of Capacity, Capacity Assessment Office, Ontario Ministry of the Attorney General.

itself indicate incompetence. Similarly, fear can affect a person's ability to make a decision, but it is important to look behind the response and to assess the individual. A person may decline a procedure, as they believe it will be very painful and they do not want to experience that pain. But it may be the case, that with careful explanation about the procedure and with options for pain relief, his or her fears may be allayed, and thus they can consent to the treatment. Other temporary factors such as shock, drugs and confusion may also impinge on someone's competence (Hobden and Mills, 2008).

Donnelly (2007) emphasises the need for a rigorous approach to expert evidence (i.e. evidence from the medical profession) and a participative element when formally assessing capacity. She discusses the problems which can arise with the quality of expert evidence (due in part to a general lack of awareness of the legal position among medical professionals), such as for example, adopting a status approach where the expert gives evidence that the individual has a mental condition such as schizophrenia and then concludes on this basis that he/she is incapable rather than applying the legal test for capacity (Grisso, 2002). In addition, a participative element in the process by the individual concerned will lead to better decision-making and will also assist in minimising the negative impact of the process on the individual involved (Donnelly, 2007). The 2005 Guidelines include key points in relation to the assessment of capacity [47] as follows:

1. People with intellectual disabilities are not a separate group of human beings who think, feel and act in a similar fashion. Their individual likes, dislikes, choices, talents, strengths and weaknesses are varied as elsewhere in society.

2. Difficulties in communication should not be confused with incapacity.

3. Presence of intellectual disability must not undermine the presumption of capacity.

47 Adapted from Ontario Ministry of the Attorney General, 2005.

4. Physical disabilities, no matter how extensive, do not equal or necessarily indicate incapacity.

5. Characteristics associated with specific syndromes cannot be presumed to be evidence of incapacity; for example, in Down's Syndrome, an extensive range of intellectual ability is encountered.

6. Institutionalisation is not an indicator of incapacity.

7. An intellectual disability is a fact of life for the person, part of who the person is. It typically dates from birth and it is not something that is only happening now to the person. The extent to which it has become a disabling condition depends to a significant extent on factors external to the person; for example, the presence, absence or variability of opportunities for early developmental nurturing and support, education (social or academic), family or community acceptance and emotional support.

8. Decision-making skills may be under-developed as a consequence of the limiting experience of restrictive environments; for example, institutional and other controlled, congregate settings, family over-protectiveness, or other externally imposed barriers to growth and development including negative expectation of progress (self-fulfilling prophecies) on the part of professional advisors.

9. Inappropriate use of traditional assessment procedures (such as IQ and related instruments) has typically led to exclusion from, rather than access to supports for the individual. (Such instruments do not predict adequacy of functioning ability to make reasoned decisions about personal care.)

10. People are not necessarily conscious of their own biases and prejudice towards individuals with disabilities. Assumptions that people with intellectual disabilities should not have homes of their own and should live in large group settings, that they are

asexual or that they should not engage in friendships or intimate relationships are examples of disabling factors that have their origins in society's prevailing attitudes and responses rather than in the needs or characteristics of the person.

11. Parents and family members can also have their biases.It cannot be assumed that being a parent or member of a family in which there is a person with intellectual disability guarantees immunity to prejudice, or up-to-date knowledge of the person or of the law. Many parents of adults with intellectual disability have assumed that children who have disabilities, unlike other children, remain forever under the parents' legal guardianship and responsibility can be willed to other family members upon death. Some parents, having always controlled the lives of their daughter or son, may be seeking guardianship in order to maintain that authority and control or to ensure that their values prevail over those of the person. Some may sincerely believe that guardianship guarantees protection from abuse.

2.8.4 Assessment instruments

Inappropriate test measures may be used to assess capacity. One such test, discussed in Donnelly (2007), is the Mini-Mental State Examination (MMSE), based on a series of questions, related to orientation, memory, concentration and language, which do not relate in any way to legal standards for capacity. Similar problems arise with the use of 'mental age' descriptors. Donnelly (2007) notes that the relevance of expert evidence based on 'global psychometric test results' as well as evidence based on references to a patient's 'mental age' have been rejected by the Official Solicitor for England and Wales. [48] Meanwhile, the British Institute of Learning Disabilities (BILD) notes that results of psychometric tests can be open to misinterpretation, and factors other than learning disability can affect results; for example, psychiatric illness or drug use (BILD, 2004).

48 The Practice Direction (Declaratory Proceedings: Incapacitated Adults [2002] 1) W.L.R. 325, cited in Donnelly (2007: 166). The Official Solicitor, an appointee to the Supreme Court, is part of the judicial system of England and Wales.

The British Medical Association and the Law Society (BMA and the Law Society, 2004) advise that GPs should not rely solely on prior reports giving an estimated 'mental age' but must ensure that a current assessment is made. They note that statements of a person's mental age may be misleading if they do not reflect the person's experience and the context for the particular decision.

Murphy and Clare (2003: 43) reviewed research that used different instruments to assess capacity of people with intellectual disabilities, with mental illness, and with dementia. The review found that the studies suggested that capacity to consent is likely to depend on at least the manner in which information is presented and tested, and the complexity of the task required. Breaking up information into smaller 'chunks', using simpler language, and even non-verbal measures was helpful for people with intellectual disability.

Other assessment instruments noted in the literature included the MacArthur Competence Assessment Tool (MacCAT-T), which can be used in making judgements about capacity in a variety of clinical situations (Grisso and Appelbaum (1998)).

2.8.5 Who can assess capacity?

The person who assesses an individual's capacity to make a decision will usually be the person who is directly concerned with the individual at the time the decision needs to be made. Capacity assessment can be carried out by different types of people depending on the circumstances: by the person caring for them (usually with regard to day-to-day decisions), by a general practitioner or healthcare professional. More complex decisions are likely to need more formal assessments. Sometimes there is no need for any type of formal capacity assessment by a professional before determining that a person does not have capacity. Sometimes legislation will determine who is required to assess capacity and sometimes it is set down in organisational guidelines.

2.8.6 Acting in the person's 'best interests'

The effect of a finding that a person lacks capacity to make a particular decision is that some other person or body will make the decision for

her/him. Donnelly (2008) argues that the rights of the individual whose capacity is being assessed must be prioritised in relation to the basis upon which decisions are made and in relation to the identification of an appropriate decision-maker.

At common law, where an adult cannot consent to treatment, the doctrine of necessity arises to assist in the decision-making process. Essentially the doctrine provides a legal justification for treating a person who does not have the capacity to consent where there is what is termed a necessity to act. The doctrine of necessity has two components: first there must be a necessity to act and second, the action must be what a reasonable person would do in the circumstances acting in the person's best interests (i.e. the expected benefits of a proposed treatment outweigh the burdens).[49] In the UK there has been a move away from deciding matters on the basis of acting in accordance with a responsible body of medical opinion. The UK Courts have decided that best interests are not limited to what would benefit a person medically, but encompass broader emotional, social, and welfare considerations [50] and must take into account the patient's values and preferences when competent, their well-being, quality of life, relationships with family or other carers, spiritual and religious welfare, and their own financial interests. Where patients are competent and have access to information, they are the best judge of what is in their interests.

According to the Department of Health's guidance on consent issues in England (DoH, 2001) it is not lawful to balance the interests of the individual against the interests of their family, the interests of health professionals, or the interests of other people living with the individual. However, they note that these interests will often be inter-linked; for example, the effect of a treatment decision on family relations should be taken into account as part of the individual's "best interests", where family support is important to the person with learning disabilities.

The Irish Law Reform Commission (LRC, 2006) favoured a 'set of composite guiding principles', which it proposed should underpin the

49 Set down in Re F (Mental Patient: Sterilisation) [1989] 2 All ER 545.

50 Re S (Sterilisation: Patient' Best Interests) [2000] 2 FLR 289.

legislation in this area and address the difficulties associated with an unsubstantiated 'best interest 'requirement in assisted decision-making. Bartlett (2008) notes that Section 4 of the Mental Capacity Act 2005 (England and Wales) provides a helpful example of a new approach to the best interests standard. It sets out some common factors that must be considered when trying to work out someone's best interests. These are discussed in the Mental Capacity Act 2005 Code of Practice (Department for Constitutional Affairs, 2007):

- Anyone working out someone's best interests must not make unjustified assumptions about what their best interests might be simply on the basis of the person's age, appearance, condition or any aspect of their behaviour.

- All relevant circumstances should be considered. Relevant circumstances are defined in Section 4 (11) of the Act as those: '(a) of which the person making the determination is aware, and (b) which it would be reasonable to regard as relevant.'

- In determining what is in a person's best interests, a decision-maker must, so far as is reasonably practicable, permit and encourage the person to participate as fully as possible in the decision. A number of practical steps to assist and enable decision-making are provided. These include:
  - using simple language and/or illustrations or photographs to help the person understand the options
  - asking them about the decision at a time and location where the person feels most relaxed and at ease
  - breaking the information down into easy-to-understand points
  - using specialist interpreters or signers to communicate with the person.

- If there is a chance that the person will regain the capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent (for example, a person with an intellectual disability may learn new skills or be subject to new experiences which increase their understanding and ability

to make certain decisions, or a person previously unable to communicate may learn a new form of communication).

- The decision-maker must take account of the person's past and present wishes and feelings (and in particular, any relevant written statement made by the person when she/he had capacity), the beliefs and values that would be likely to influence the decision if she/he had capacity, and the other factors that she/he would be likely to consider if she/her were able to do so.

- Decision-makers must take into account, if it is practicable and appropriate to consult them, the views of anyone named by the person as someone to be consulted, anyone engaged in caring for the person or interested in their welfare, any person appointed under a lasting power of attorney, and any deputy appointed for the person by the court.

According to Donnelly (2007), the conception of best interests under the Mental Capacity Act, 2005, in England and Wales constitutes a significant improvement on the traditional approach to this standard: specifically, the views of the person lacking capacity must be taken into account and it imposes an obligation on decision-makers to encourage participation as much as possible. This recognises that a person may still make a valuable contribution to a decision-making process even if she/he lacks capacity and it also diminishes the risk of conflict between a decision-maker and a person lacking capacity. Secondly, Donnelly (2008) emphasises that the requirement to take account of the past wishes and feelings and the relevant beliefs and values shows continuing respect for the right of autonomy of the person now lacking capacity. The person proposing to take the action must have reasonable grounds for believing that the action is in the best interests of the person who lacks capacity.

Head 3 of the Scheme of Mental Capacity Bill 2008 provides details on the standard to be applied in determining a person's 'best interests'. This involves:

- Consideration of whether it is likely that the person would at some time have capacity in relation to the matter in question, and when that would likely be.
- Encouraging the participation of the person in question, improving his or her ability to participate as fully as possible in any act done for him or her and any decision affecting him or her.
- Consideration of the person's past and present wishes and feelings and of the beliefs and values they hold which would likely influence their decision if they had capacity.
- Consultation with relevant parties.

2.9 Supports for women with intellectual disability and contraceptive usage

Grover (2002) argues that it is essential that the general health needs of women with intellectual disability be viewed from the perspective of current standards of care and management while making adjustments to match individuals' needs, abilities and other medical conditions. Her research demonstrated that the contraceptive and gynaecological needs of the intellectually disabled population do not differ widely from those of the general population.

Grover's research, conducted in Australia, examined the frequency of requirement for surgical management, compared with other forms of management, among young women with intellectual disability. The women were referred to her (in her role as gynaecologist) for management of menstrual and contraceptive problems. In all, a total of 107 young women with intellectual disability were seen over a nine-year period (1990-1999). Of this group, there were 15 who had severe intellectual disability and high support needs, and 92 women with moderate intellectual disability, and lower support needs.
The results of Grover's research showed that:

- For 2 of the 107 young women, surgical approaches were required to manage their menstrual problems or contraception-related issues.

- For the remainder of the women, information, advice or medical management were sufficient.

Grover considered that successful management of the contraceptive and menstrual concerns of young women with significant intellectual disability and high support needs can be readily met by approaches normally taken with non-disabled women.

Griffin et al.'s study (1994) also demonstrated the ability of women with intellectual disability, even those with high support needs, to gain additional skills in their personal menstrual management. Grover (2002) concluded by asserting that, as surgical interventions are infrequently required, GPs with appropriate resources and support should be able to confidently care for young women with significant intellectual disability.

Keywood advises that creating time and being generous with time is essential, so that the decision-making of people with intellectual disabilities is facilitated and supported and their consent to treatment is achieved by a reflective and informed process (2003). Similarly, Grover (2002) notes that appropriate allowance for the longer consultation time involved in the care of clients, and access and referral by doctors to appropriate education and resources are additional requirements.

Servais (2006) argues that healthcare professionals can best advocate for and support the sexual health needs of people with intellectual disability by assessing contraception, hygiene management, STDs, and abuse prevention from the individual rather than the caregiver perspective to the maximum extent possible. The needs of people with intellectual disability vary greatly according to factors such as the individual's life milieu, knowledge, disability severity, age and gender, rendering it impossible to issue global healthcare guidelines for people with intellectual disability. Therefore, an individualised, person-centred, multidisciplinary approach that incorporates caregivers, medical staff, educators, and the individual should be used to provide comprehensive sexual healthcare to persons with intellectual disability. This level of care may be achieved in specific facilities when available, but can also occur wherever there are medical and health professionals who are committed to a collaborative and global approach to sexual health concerns (Servais et al., 2002).

It may be difficult for a woman with intellectual disability to discuss issues of sexuality and contraception with parents or carers, as they may

perceive sexual activity as adding further complications to an already complex life. Martin (2002) argues that an adult with learning disabilities should no longer need her parents' permission to obtain contraception; however, if she is still living at home, she may have little opportunity to discuss these issues with a professional.

Key principles in providing support to women with intellectual disability in the area of contraception were identified in the literature as follows:

- Decisions around the use of contraception should be based upon the informed choice of the person with intellectual disability; any assistance they require should be given as part of the multi-disciplinary approach (BILD, 2000)

- The rights of a person who has a disability to have freedom of choice should be supported and the least restrictive option in relation to the management of their menstruation and/or contraception should be exercised (Office of the Public Guardian, 2007).

- Contraceptive treatment should not be decided on the basis of a woman's disability alone (Office of the Public Guardian, 2007).

- While recognising that women with a disability have the right to be protected from sexual abuse and exploitation, consent should not be given to contraception as the sole strategy to minimise the potential risk of harm in these situations (Office of the Public Guardian, 2007).

- Consent to a contraceptive treatment in situations of potential abuse should only be given in cases where issues of the person's freedom of action and exposure to risk have been considered, and it is necessary to protect the woman from unwanted pregnancy (Office of the Public Guardian, 2007).

- Women with a disability should be supported to have access to appropriately trained family planning professionals for counselling regarding the need for, and method of, contraception treatment prior to its use (Office of the Public Guardian, 2007);

people may require more than one session of advice and information (BILD, 2000).

- The agencies providing advice should be encouraged to produce information in accessible formats for people with intellectual disability (BILD, 2000).

- Family members may have views about contraception; these only need to be taken into account if the person with intellectual disability requests it (Office of the Public Guardian, 2007).

2.10 Sterilisation

Parents commonly feel protective of their daughters, and may have concerns and fears of their vulnerability to sexual exploitation. In the past such concerns have led (and may continue to lead) parents to inquire about or request sterilisation to prevent an unwanted pregnancy. Parents may also be concerned about adverse effects associated with menstruation (discomfort, difficulties in hygiene, missing school/work for five to seven days per month). Notwithstanding the ethical issues associated with sterilisation, Carpenter argues that many parents are unaware of the medical risks associated with surgery (Carpenter, 1992). Use of general anaesthesia is associated with increased risks for persons with Down's syndrome because of concomitant physical impairments (for example, persons with Down's syndrome often have pulmonary and cardiac abnormalities), and postoperative complications can also occur (such as pulmonary embolism, cardiac malfunction, atelectasis and aspiration pneumonia) (Grimes, 1997).

According to Stansfield, Holland and Clare (2007), special provisions apply to sterilisation, as it is a significant and usually irreversible procedure in the context of which the best interests of the person may not be obvious. The issue of non-consensual sterilisation has not come before the courts in Ireland (LRC, 2005). The Law Reform Commission in their Consultation paper (LRC, 2005) note that if the issue of non-consensual sterilisation came up for judicial consideration the approach preferred would be that it would only be sanctioned for therapeutic purposes, i.e. being required for the person's mental or physical health as opposed to non-therapeutic sterilisation used for contraceptive purposes (LRC, 2005).

The right to have children has been recognised in a marital context as one of the unenumerated rights guaranteed by Article 40 of the Constitution as being essential to the human condition and personal dignity; the constitutional right to bodily integrity and Article 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) are also relevant in this context (LRC, 2005: 162). The Commission on the Status of People with Disabilities (1996) recommended that in any case where sterilisation was being considered, every effort should be made to ensure informed and free consent exists. Where informed consent is not possible, it recommended:

- that a court should determine that there is a necessary and just cause
- that other methods of contraception are unworkable
- that fair procedures are observed, including medical and psychological assessment of the person's welfare and rights
- that there be full consultation with parents and carers
- that independent advocacy should be made available to the person.

The Law Reform Commission recommended that any sterilisation of an adult (who lacks the capacity to make a decision to consent to or decline the procedure) where there is no serious disease or malfunction of the reproductive organs would require the prior consent of the High Court. The Scheme of Mental Capacity Bill, 2008 confirms this by providing that the High Court shall have exclusive jurisdiction to determine any issues concerning a non-therapeutic sterilisation in the case of a person who lacks decision-making capacity.

2.11 Key findings

The key findings from this section on pregnancy risk, contraception and consent to medical treatment are presented below:

Contraceptive use

- The pattern of contraceptive use amongst women with intellectual disability differs widely from that of the non-disabled population. Longstanding research confirms the Pill, Depot Medroxyprogesterone Acetate and IUDs are the only methods

used by most women with learning disabilities, with barrier methods being reported as unheard of.

- One study in Belgium (Servais et al., 2002) found that women with intellectual disabilities were more likely to be treated with sterilisation or Depot Medroxyprogesterone and less likely to be prescribed oral contraceptives. Another study in England showed that the women were not well informed about the nature of the medical interventions arranged for them or possible side-effects.

- Reliance on low/no maintenance methods as outlined above assumes that women with learning disabilities are incapable or unreliable when it comes to managing their own fertility (McCarthy, 1999).

- The following factors were associated with an increased probability of using contraception (Servais et al., 2002):
  - Residing in an institution
  - Living in an institution where contraception is required or advised
  - Living in an institution where sexual intercourse is not prohibited
  - Having a milder disability.

  The authors noted the low influence of personal or medical factors in the women's use of contraception.

- Small-scale research in England (McCarthy, 1998) demonstrated that decision-making about contraception was done by others (including doctors, parents, and family members) on behalf of women with intellectual disabilities. McCarthy (1998) asserts that while some women with learning disabilities would find making decisions about contraception difficult and would find it hard to manage the practicalities of some methods, women with learning disabilities are not given sufficient or appropriate information and support to make these choices themselves.

- In relation to capacity to consent to medical treatment, it has been recognised that contraceptive treatment should be treated in the same way as all other medical procedures, i.e. be subject to the same rules that apply for medical treatments in general (Namhi, 2003).

- If the question of routine or minor procedures arises, then efforts should be made to ascertain if the person has capacity to decide. There is provision for informal decision-making for health care and treatment in the Scheme of Mental Capacity Bill, 2008. The High Court has exclusive jurisdiction to determine any issues concerning a non-therapeutic sterilisation in the case of a person who lacks decision-making capacity.

Legislation governing capacity

- Within the Scheme of Mental Capacity Bill 2008 capacity is defined as 'the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made'. [51]

- The draft Bill reflects the international move towards a functional approach to capacity where a person lacks the capacity to make a decision if she/he is unable to:
  - Understand the information relevant to the decision;
  - Retain that information;
  - Use or weigh that information as part of the process of making the decision;
  - Communicate her/his decision.

- Informal decision-making is provided for in the draft Bill, which gives medical practitioners and others who perform an act in connection with the care or treatment of another person whose decision-making capacity is in doubt, immunity from liability if they comply with the conditions in the draft legislation when treating patients.

51 Head 2(1).

- The Scheme of Mental Capacity Bill 2008 does not apply to consent to have sexual relations. [52]

- Criticism of the Law Reform Commission Bill centred on: the proposed definition of capacity being too open-ended; the lack of provision relating to advocacy; that there should be inclusion of a special requirement requiring medical professionals to include family members or carers of a person lacking capacity in treatment decisions; and a requirement that the person lacking capacity should be consulted regarding their choice of personal guardian (Donnelly, 2008).

International legislation governing capacity

- In England and Wales, the corresponding legislation is the Mental Capacity Act, 2005, which provides a statutory framework for substitute decision-making for those who lack capacity. Many of the provisions in the Scheme of Mental Capacity Bill, 2008, are similar to the provisions in this legislation.

- Good practice provisions of the UK's Mental Capacity Act 2005 were identified as follows:
  - It adopts a functional approach, where capacity is decision-specific and time-specific rather than global or permanent; the implication is that before any declaration of incapacity, consideration needs to be given as to whether it would be possible either to improve the person's relevant functional abilities and/or to simplify or otherwise amend the situation to improve the person's capacity (Murphy and Clare, 2003).
  - It introduces a legal duty to consult with others involved in caring for the person or interested in his/her welfare before carrying out acts in relation to a person who lacks capacity.
  - It requires steps to be taken to develop capacity and imports a right to comprehensible information (S. 1 (3); S 3 (2)).
  - Under the Act, a person is required to make an assessment of capacity before carrying out any care or treatment. The

52 Head 20(e).

more serious the decision, the more formal the assessment will need to be.
  - It cannot be decided that somebody lacks capacity based on their age, appearance, condition or behaviour alone.
  - The Act provides for an advocacy structure, the Independent Mental Capacity Advocate (MCA) service.

- In Ontario, Canada, the relevant statute in this area is the Health Care Consent Act 1996, which covers treatment, admission into a long-term facility, and decisions about personal assistance services. Similar to the Irish draft legislation, capacity is defined as having an understanding of the relevant information and an ability to appreciate the reasonably foreseeable consequences. The Statute defines the information requirements necessary for informed consent. The Ontario Capacity Assessment Office recommended that the emphasis be on the quality of the decision-making process, not the actual course of action in which a person engages. This requires exploration of the particular line of reasoning employed by the person in making decisions, and whether or not those decisions are consistent with a personal belief system, known values and reality.

- In Ireland it is the responsibility of the relevant medical practitioner to ensure that a person has capacity to make a healthcare decision. In the absence of explicit assessment guidelines, there is a danger that incapacity might be inferred solely on the grounds that the individual has a disabling medical or psychiatric condition. There has been recognition of the need for guidance for medical practitioners in relation to:
  - How capacity to make healthcare decisions should be assessed
  - What action the law requires if a person is judged not to have the capacity to make a healthcare decision (LRC, 2006: 32).

Good practice in assessment of capacity

- When assessing capacity, a number of good practice guidelines and principles were noted in the literature review, including:

- The introduction of a standard assessment protocol, which would reduce bias and introduce consistency in the way that mental capacity assessments are conducted (Ontario Ministry of the Attorney General, 2005)
- Development of a model consent policy and consent forms, together with an information leaflet (Department of Health, 2001, 'Good Practice in Consent Implementation Guide: consent to examination or treatment')
- When formally assessing capacity, the need for a rigorous approach to expert evidence (i.e. evidence from the medical profession) was emphasised. In addition, it was noted that a participative element involving the person with an intellectual disability would lead to better decision-making and reduce the negative impact of the process on the person whose capacity is being assessed (Donnelly, 2007)
- The need to recognise the heterogeneity of people with intellectual disabilities (Servais et al., 2002)
- Difficulties in communication should not be confused with incapacity
- The right of the competent individual to make the wrong decision, even for reasons that may be irrational or non-existent to health professionals (Hobden and Mills, 2008)
- A recognition that the mere presence of emotional responses such as panic or irrationality does not in itself indicate incompetence (Hobden and Mills, 2008)
- Recognition of the fact that decision-making skills may be under-developed as a consequence of the limiting experience of restrictive environments (such as institutional and other controlled, congregate settings), family over-protectiveness, or other externally imposed barriers to growth and development including negative expectation of progress (self-fulfilling prophecies) on the part of professional advisors (Ontario Ministry of the Attorney General, 2005).

- The conception of the 'best interests' standard under the Mental Capacity Act 2005 in England and Wales was considered to contain good practice, specifically (Donnelly, 2008):

- The requirement that the views of the person lacking capacity must be taken into account and the fact that it imposes an obligation on decision-makers to encourage participation as much as possible
- The requirement to take account of the past wishes and feelings and the relevant beliefs and values which shows continuing respect for the right of autonomy of the person now lacking capacity
- The person proposing to take the action must have objective reasons for thinking an action is in the best interests of the person who lacks capacity to consent to it.

Supports for women with intellectual disability in the area of contraceptive provision

- In relation to supports for women with intellectual disability and contraception the following issues were identified:
  - It is essential that the general health needs of women with intellectual disability be viewed from the perspective of current standards of care and management while making adjustments to match individuals' needs, abilities and other medical conditions (Grover, 2002)
  - The contraceptive and gynaecological needs of the intellectually disabled population do not differ widely from those of the general population (Grover, 2002)
  - The successful management of the contraceptive and menstrual concerns of young women with significant intellectual disability and high support needs can be readily met by approaches normally taken with non-disabled women (Grover, 2002)
  - Appropriate allowance for the longer consultation time involved in the care of women with intellectual disability. Access and referral by doctors to appropriate education and resources are additional requirements (Grover, 2002). In Ireland the Equal Status Acts 2000-2008 require service providers to provide reasonable accommodation for people with disabilities by providing special treatment and facilities if without such treatment or

facilities it would be impossible or unduly difficult for the person to avail himself or herself of the service.The special treatment could arguably include longer consultation time, etc.

- An individualised, person-centred, multidisciplinary approach that incorporates caregivers, medical staff, educators, and the individual should be used to provide comprehensive sexual health care to persons with intellectual disability (Servais et al., 2002).

3.0 Capacity to consent to sexual relationships

3.1 Introduction

Historically in Ireland, the UK, Australia, America and other Western countries people with intellectual disabilities and mental health problems were considered 'unfit' to reproduce and become parents, with implications such as sexual relationships being discouraged for people residing in institutions (Barker, 1983; Fennell, 1996; Trent, 1994). This attitude began to change in the 1970s through the discussion of disability rights (Shakespeare, 2000, Rioux, 1997) and the introduction of the concept of normalisation (Emerson, 1992; Wolfensberger, 1980 cited in BPS, 2006:105), which led to a growing empowerment of people with learning disabilities and a widening acceptance of their rights in relation to recognition of their sexual needs. As a result, sex education materials began to be written that addressed issues specific to people with intellectual disability (McCarthy and Thompson, 1998; Cambridge, 1997).

Meanwhile, research has demonstrated the high incidence of sexual abuse or exploitation of people with intellectual disabilities and their vulnerability to such abuse because of their social and/or cognitive differences (McCarthy, 1999; Sobsey, 1994). Brown (2004) asserts that women with learning disabilities face double oppression at the intersection of gender and disability, and this renders them particularly vulnerable to sexual violence and exploitation. Vulnerability, Brown (2004) contends, is usefully viewed in the context of a social model of vulnerability. This model locates the extra risks to women with learning disability, not in their impairments per se, but in the extent to which they are placed in situations which expose them to risks that other women would not be exposed to, and in discriminatory responses experienced by women from agencies.

Assessment of capacity to enter sexual relationships has received increased attention in recent years (Murphy and Clare, 2003; Lyden, 2007; Kennedy and Niederbuhl, 2001) due to the increasing recognition of the rights of people with disabilities. There is general agreement that people should be enabled and encouraged to take decisions for themselves when possible. There has been increasing concern and recognition of the need to both empower people with intellectual disability to make their

own sexual choices and to protect them from abuse. The main difficulty is determining whether a person with an intellectual disability has the capacity to consent to a sexual relationship, and if so whether the person is consenting to a particular sexual relationship (Eastgate, 2008).

The following discussion of capacity, consent and sexual relationships provides an overview of the statutory framework within which individuals with intellectual disabilities' capacity to explore and enjoy sexual relationships autonomously is regulated. It goes on to consider current debates in this area, including the argument that in trying to protect vulnerable people the law is reducing their freedom, in so far as sex and intimacy are concerned to the extent that some people deemed as 'mentally impaired' could run the risk of prosecution. This section will look to examples of good practice from other jurisdictions attempting to achieve a balance between protection and autonomy.

3.2 Recognition of rights to sexual relationships for people with intellectual disabilities

Article 23 1 (a) of the UN Convention on the Rights of Persons with Disabilities recognises the 'right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses'. In Ireland, The Law Reform Commission (2006) has emphasised that where a person has been found to lack capacity, this results in a restriction or removal of fundamental human rights; therefore, the issues of capacity and rights are inextricably linked (LRC, 2006).

With regard to sexual fulfilment for people with intellectual disabilities, a number of authors have recommended the adoption of a rights-based approach to the development of legislation incorporating protection without discrimination for adults with intellectual disabilities (Donnelly, 2008; Graydon, Hall and O'Brien-Malone, 2006; Keywood, 2003b; Brown, 2004; Brown, 1996). In reviewing the law and procedures for people whose capacity is in question and/or is limited note must be taken of Ireland's human rights obligations and of international human rights principles. Any change to the law on capacity must comply with those obligations and be guided by the principles underpinning those obligations.

The following rights, obligations and principles are relevant to capacity and intellectual disability:

- The need for laws, procedures and practices relating to the protection of adults lacking capacity to meet benchmarks provided by constitutional and human rights law.
- The right to be recognised as a person before the law. [53]
- The right to freedom from discrimination on the grounds of disability [54] and the right to reasonable accommodation by the provision of special facilities and treatment.
- The requirement that States take appropriate measures to provide persons with disabilities with access to the support they may require in exercising their legal capacity. [55]
- The recognition and protection of the rights of the person lacking capacity, including the recognition of the right to sexual expression for people with intellectual disabilities.
- Emphasis on a woman's abilities rather than her disabilities; her participation in society should be encouraged notwithstanding her lack of capacity in certain areas.
- The promotion of services that seek to integrate empowerment and protection within their approaches to supporting the sexual lives of people with intellectual disabilities.

While the right to enter into a sexual relationship has not been enshrined in legislation, both Irish case law and the Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) go some way

53 Article 6 of the Universal Declaration of Human Rights; Article 16 of the International Covenant on Civil and Political Rights.

54 Equal Status Acts 2000 to 2004. The reasonable accommodation provisions are subject to a nominal cost exemption.

55 Article 12 of the UN Convention on the Rights of Persons with Disabilities, 2007.

in recognising people with intellectual disabilities' need for sexual fulfilment.

In this regard, the Supreme Court in Re a Ward of Court (withholding medical treatment) (No. 2) [56] recognised that a loss of mental capacity does not result in any diminution of one's personal rights under Article 40.3.1 and Article 40.3.2 of the Constitution. In Ireland the courts have recognised that these rights include the right to privacy, self-determination and the right to marry and found a family (LRC, 2005). The right to privacy and the right to marry, however, have not been interpreted in the courts as absolute and unqualified in nature.

Article 8 and Article 12 of the ECHR are also relevant. Article 8 deals with a person's right to respect for privacy and family life. Article 12 provides for the right for men and women of marriageable age to marry and found a family within the boundaries of the national law. It has been argued that the right to marry, or even to found a family, implies the existence of a sexual relationship, but this falls short of providing a 'right' to have sex (Evans and Rodgers, 2000).

Meanwhile, Article 8 would seem to go further in enabling individuals to engage in sexual activity when it provides an individual with the 'right to respect for his private and family life' (Evans and Rodgers, 2000). In relation to Article 8, the European Commission on Human Rights has stated:

> The arrangement of sexual relations and family planning come on principle within the sphere of private and family life as protected by Article. 8, paragraph 1 [57]

Furthermore, in the same case (Bruggeman and Scheuten v Germany) the European Commission on Human Rights stated:

> [An individual] must also have the possibility of establishing

56 [1996] 2 IR 73, 126 per Hamilton CJ.

57 Decision by the European Commission on Human Rights on Application No. 6959/75, Bruggemann and Scheuten against Federal Republic of Germany, http://cmiskp.echr.coe.int/tkp197/portal.asp?sessionId=17942956&skin=hudoc-en&action=request

> relationships of various kinds, including sexual, with the other person. In principle, whenever the state sets up rules for the behaviour of the individual within this sphere, it interferes with respect for private life and such interference must be justified in the light of Article 8 (2). [58]

Keywood (2003b) observes that the right to sexual expression has long been recognised as a facet of the basic right set out in Article 8. [59] However, Evans and Rodgers (2000), writing in the UK context, argue that the civil law is not consistent in its approach as to the ability of an individual to engage in sexual intercourse or other sexual acts, and whether rights to do so exist in law.

Meanwhile, criminal law in Ireland imposes several offences that limit the exercise of any perceived rights granted through civil law. When considering personal relationship issues, capacity to enter a sexual relationship is a matter which is ruled by the criminal law, which requires that to enter into a sexual relationship each of the parties must be of age and consent to the act. The question of the capacity of people with intellectual disabilities to engage in lawful sexual relationships arises. As stated previously, Section 5 of the Criminal Law Sexual Offences Act 1993 criminalises sexual intercourse with a person who has a mental impairment as defined.

3.3 Protection from exploitation versus need for autonomy

The Law Reform Commission (LRC), in its report on vulnerable adults and the law (LRC, 2006), noted that the subject of the capacity of adults with limited decision-making ability to enter into relationships is a difficult one, which has yet to be widely explored in Irish society. The Commission acknowledges that historically the law has approached this subject with 'a form of benign paternalism based on the concept of what is considered to be in their best interests' (LRC, 2005). The difficulty in designing legislation that would provide for a balance between the need to protect vulnerable individuals from exploitation and the need to respect an individual's autonomy and capacity to engage in voluntary and

58 (1997) EHRR 244.

59 Based on an English case, Dudgeon v United Kingdom (1982).

freely chosen relationships has been recognised (LRC, 2005). Canadian legal researchers Benedet & Grant's review of case law and social science literature on sexual assault and women with mental disabilities [60] demonstrated that sexual autonomy and freedom from sexual violence were not mutually exclusive goals but instead are closely linked and mutually reinforcing. Satisfying both of these goals is not easy, and progress towards these goals is impeded for women with intellectual disability by the competing stereotypes of hypersexuality and asexuality (2007: 279).

In essence, the purpose of legislation should be to respect the private rights of all citizens to enjoy family contact and personal or sexual relationships (reflected in civil law) and should, so far as is practicable, protect such persons against sexual exploitation (reflected in criminal law) (BMA and the Law Society, 2004). Benedet & Grant (2007) examine the debate about capacity and how high the threshold should be set. They propose that the threshold needs to be high enough to protect women who do not have the ability to understand what they are consenting to, especially since such women are more likely than others to be repeated targets of sexual assault. Equally, it should not be so high that women with intellectual disability are prohibited by law from having a sexual life.

In both civil and criminal contexts, judgements about individuals' capacity to consent in personal relationships are extremely important. Overall, however, as noted by the British Medical Association and the Law Society (BMA, and the Law Society, 2004), current case law is more concerned with the provisions available in the criminal law to protect vulnerable people from potentially abusive relationships than with their civil law rights to enter into voluntary relationships.

3.4 Sexual violence and exploitation

The research has shown that people with learning disabilities, and particularly women, are not only just as likely to experience sexual abuse in the same way as other adults and children do, but that they are particularly vulnerable (Sobsey, 1994; McCarthy, 1999; McSherry, 1998).

60 The authors define 'mental disability' as including a developmental disability, a psychiatric disability, or some other chronic nonepisodic mental disability.

Studies consistently show that women with learning disabilities are at risk from abuse, predominantly by men within their networks, including other service users, staff, family members, neighbours and friends of the family (McCarthy, 1999; McCarthy and Thompson, 1997; Brown, Stein and Turk, 1995; Hard and Plumb, 1987; Stromsness, 1993).

People with intellectual disability may experience a high incidence of sexual assault and sexual exploitation because of their 'lack of power over resources, relationships, decision-making and information and the fact that social attitudes may stigmatise them as deviant or of little value (Rosser, 1990; Hayes & Craddock, 1992: 75; Wilson, Nettlebeck, Potter and Perry, 1996; Razack, 1994).

Most studies have reported that the majority of the intellectually disabled victims of sexual exploitation have mild or moderate intellectual disability, but this may be because most accounts of exploitation come to light through the victim's disclosure (Brown et al., 1995; Turk and Brown, 1993). Murphy (2007) contends that those cases of sexual exploitation perpetrated against individuals with more severe disabilities may not in fact be recognised.

3.4.1 Definition of abuse

Brown and Turk (1992) define abuse as occurring 'where sexual acts are performed on or with someone who is unwilling or unable to consent to those acts'. These authors include both cognitive ability and inequalities of power within the assessment of whether an individual is able to consent – that is, 'whether the person had the ability to consent to sexual relationships in general and/or was able to do so without undue pressure in this particular situation'.

Matthews (1994) has addressed the sexual abuse of a person with learning disabilities, arguing sexual abuse can take place 'where that person's apparent willingness is unacceptably exploited'. McCarthy (1999) notes that this development of the definition strengthens the argument on the existence of 'barriers' to consent within certain relationships (Brown and Turk, 1992; Sgroi, 1989). According to McCarthy, this is useful as it indicates that although a person with learning disabilities may have

understood and been willing to engage in sexual contact, they may still have been abused because of the position or motivation of the other person (McCarthy, 1999: 69).

McCarthy and Thompson (1997) have progressed this work by drawing a distinction between abuse as defined by the law in England and Wales (for example, prior to the Sexual Offences Act, 2003, laws existed to afford protection against abuse involving a person with a severe learning disability, staff abusing a client or someone overpowering the person using physical violence) and abuse as defined by inequality in a relationship, significant difference in ability levels or where one person's sexual needs are met at the expense of the other's.

McCarthy (1999) argues that laws designed to relate to adults without learning disabilities may be applied to adults with learning disabilities without any consideration given to the limited capabilities and pressures that they may have faced. This is particularly so in cases of rape or sexual abuse, which often stand or fall on the issue of consent. Consent will often be interpreted very simplistically, with no account being taken of why a person with learning disabilities may have consented. O'Hara & Martin (2001) assert that the lack of power many people with intellectual disability face in their relationships may make it difficult to be sure whether consent has truly been given.

3.5 Approaches to determining capacity

Three broad approaches that might be useful in assessing capacity have been differentiated (Murphy and Clare, 2003):

> **Outcome approach** argues that where an individual makes a decision that differs from most other people's, his or her capacity should be called into question.
>
> **Diagnostic (status) approach** involves inferences based on a person's membership of a specific population sharing some characteristic, such as gender, age, 'race' or sexual orientation. Historically this approach has been used to limit the decision-making of men and women who need or receive treatment and/or support because of a 'mental disorder'.

> **Functional approach** is based on establishing (1) a person's functional abilities, behaviours or capacities (Grisso, 1986), that is, what he or she understands, knows, believes or can do which is directly relevant to the legal context at issue and (2) the extent to which these functional abilities meet the demands of a particular situation within a given legal context.

According to Myron et al. (2008) the functional approach has been increasingly preferred when assessing capacity and is increasingly recommended to professionals such as medical practitioners and psychologists in their professional guidance. [61]

The implication is that before making any declaration of incapacity, consideration needs to be given to whether it would be possible either to improve the person's relevant functional abilities (for example, by ensuring that he/she is offered education or additional support) and/or to simplify or otherwise amend the situation to improve the person's capacity (Murphy and Clare, 2003).

Brown (2004: 44) critiques the functional model and argues that it tends not to explore suggestibility and the effect of gendered power and stereotypical gender roles on the ability of women with learning disabilities to make sound and safe decisions in their relationships and sexual lives. She suggests that a model of capacity should both maximise the woman's involvement in decision-making and, when it comes to serious abuses, help her to seek refuge, justice and redress (Brown, 2004).

3.6 Setting the standard for determining capacity to consent to sexual relationships

Much research on decision-making capacity has concerned consent to treatment (Grisso & Appelbaum, 1998; Arscott, Dagnan and Stenfert Kroese, 1999; Wong, Clare, Holland, Watson and Gunn, 2000). Murphy

61 For example, Assessment of Mental Capacity, British Medical Association/Law Society (2004); Assessment of Capacity in Adults: Interim Guidance for Psychologists, The British Psychological Society (2006). See also Suto, Clare & Holland (2002).

(2003) has observed that there has been far less consideration of capacity in the context of consenting to sexual relationships. In most European countries there is no requirement that someone engaging in sexual activity should exercise 'informed consent' of the kind required for medical treatment (i.e. to be informed and to choose voluntarily). Murphy and Clare (2003) note that there seems to be no need in law for a person to demonstrate that he or she understands the nature of sexual activity, its benefits and risks and possible alternatives. According to the British Medical Association and the Law Society (BMA and the Law Society, 2004), deciding to enter into a sexual relationship with another individual is a personal decision, which does not generally require any formal contract or test of capacity. In Ireland men and women can give legal consent to either opposite or same sex relationships at the age of 17. [62]

In this regard, legislation on mental capacity in England and Wales, the Mental Capacity Act 2005, does not cover people who lack capacity to consent to have sexual relations, as it was considered that such a decision was so personal to the individual concerned that it could not be made on behalf of a person.

McCarthy and Thompson (2004) state that in the learning disability field, people must have free choice and informed consent when it comes to sexual relationships. They considered that the conditions that should exist for free choice included the following:

- For valid consent to sex, women with learning disabilities must know that sex, especially when initiated by a more powerful person, is not required and compulsory.

- People must have sufficient communication skills to be able to make their choice (to engage in sexual activity or not) known to the other party. This means that either verbally or through an alternative communication system known to both parties they must be able to give/deny/withdraw consent at any stage in the activity. Silence or non-communication must not be interpreted as consent.

62 The Criminal Law (Sexual Offences) Act 2006 established a common age of consent to sex at 17 for males and females, whether it is a heterosexual or homosexual relationship.

- There needs to be a reasonable degree of equality between the parties, so that both parties have sufficient power to make the choice to engage or not engage in sex, without fear of adverse consequences.

McCarthy and Thompson (2004) consider other dimensions relevant to an understanding of sex, including:

- Having some knowledge about society's laws and norms about sex, including those related to privacy.

- When assessing a person's ability to consent, it is important to distinguish between adults with learning disabilities' sexual experience and their understanding of that experience; for example, people who are sexually abused may come to consider this as a normal part of their life.

- Not knowing what is legal and illegal leaves people very vulnerable to exploitation, as they can easily be deceived into thinking that certain acts are normally accepted, when in fact most society regards them as contravening important boundaries.

- People with learning disabilities also need to know what is considered usual and unusual sexual behaviour.

In relation to the definition of capacity to consent to sexual intercourse, or activities short of intercourse, at minimum it has been suggested that a level of understanding of the sexual act is required (Evans and Rodgers, 2000). The question of whether the law should impose a greater level of understanding, for example, that of understanding the possible consequences, such as pregnancy or the risk of contracting sexually transmitted diseases, has been examined. The former, the simple fact of understanding the sex act, is a lower standard, and would enable some individuals to consent to sex. A higher standard, that of understanding the sexual act and its consequences, would restrict the ability of many intellectually disabled adults to consent but would provide

a higher degree of protection for potentially vulnerable adults (Evans and Rodgers, 2000).

The issue of how to define capacity to consent to sexual relationships was considered by the British Medical Association and the Law Society (BMA and the Law Society, 2004). Entering into a personal relationship is a personal decision, which does not require any formal contract or test of capacity. Where the situation arises, the common law test of capacity to consent to sexual relations follows the usual form. This says that the person must be able to:

- Understand and retain information about what is proposed and its implications.

- Exercise choice. (It is important to consider whether one party is in a position of power which will influence the ability of the other party to consent.)

Murphy and Clare (2003) note that this implies that at a minimum people would need to understand what sexual intercourse was and that pregnancy and/or sexually transmitted diseases were risks (as well as being able to make a free choice). The BMA and the Law Society (2004) recognised the importance of taking into account the particular circumstances of the individuals involved; for example, whether one person is in a position of power, which influences the ability of the other to consent in an unpressured way.

Murphy and Clare (2003) observed that this definition of capacity was not always accepted in the courts. For example, in one case in England, R v Jenkins, a care worker was acquitted of the rape of a woman with severe intellectual disability, despite forensic evidence of his guilt, because he argued that the woman consented and the judge accepted a very low standard for consent (Murphy, 2000). [63] The woman had only a very basic understanding of the names of a few body parts and unquestionably no concept of what sexual intercourse or pregnancy meant (O'Callaghan and Murphy, 2007). This case illustrated the significance of the definition

63 The judge ruled that free and informed consent was not necessary (McCarthy and Thompson (2004).

of capacity to consent to sexual relations, and the need for an adequate level of protection of vulnerable women with intellectual disability.

Gunn (1996) observed that the definition of capacity is crucial in establishing a balance between a proper empowerment to exercise sexual rights and effective protection from abuse. Murphy and Clare (2003) note that the higher the requirement for knowledge and understanding of sexual activity, the better the protection from abuse, but the more that people with learning disabilities may be prevented from exercising their sexual rights. Setting the 'sexual knowledge' criterion too high would disadvantage people with more severe disabilities in exercising their sexual rights. Meanwhile, setting it too low would result in inadequate protection for women with intellectual disabilities.

Murphy and O'Callaghan (2004) have explored whether a minimum criterion could be set for capacity to consent to sexual relationships, i.e. when does a person 'know enough' to be safe, so that they can be protected from abuse whilst at the same time maintaining a right to freedom of sexual expression. One alternative which they proposed would be to set the criterion in terms of a social minimum of knowledge required to engage in sexual relationships. The authors used the analogy of consent to medical treatment and argued that capacity to consent to sexual relationships should similarly require people to understand what sexual relationships are, the risks, benefits and alternatives of such relationships and the fact that they have free choice about engaging in them.

Kaeser (1992) has argued that knowing all this in any detail would be far too restrictive, and that people should merely need to be able to consent to the sexual activity, while their staff and carers could know about and protect them from harmful consequences. Murphy & O'Callaghan (2004) contend that there is a careful balance to be achieved between requiring people to know enough without requiring them to know everything. A less restrictive test was that put forward by the Foundation for Learning Disabilities in the UK, which would require that people would know:

1. That sex is different from personal care;
2. That penetrative vaginal sex can lead to pregnancy; and
3. That penetrative anal sex is associated with a risk of HIV/AIDS

(Home Office, 2000: 71)

According to Stavis and Walker-Hirsch (1999), until recently in the United States there was a diagnostic criterion (minimum IQ) applied in order to determine a person's capacity to consent to sexual relationships. Wacker, Parish and Macy (2008: 88) contend that IQ and mental-age testing remain the most frequently used measures of competence, despite longstanding concerns about the validity and reliability of these tests (see paragraph on assessment instruments in Section 2.8.4 above). Nowadays different states vary in their approaches to determining capacity to consent to sexual relationships.

In an effort to try and operationalise criteria for capacity to consent, a US study conducted by Kennedy and Niederbuhl (2001) examined the views of over 300 psychologists on the criteria required for determining capacity to consent to sexual relationships. Participants were asked to grade 56 statements from 'most important' (5) to 'least important' (1). The results demonstrated that the following eight abilities were judged absolutely necessary (mean rating of 4.5 or more) to demonstrate capacity:

- Individual can say or demonstrate 'no'.
- Individual knows that having intercourse can result in pregnancy.
- Individual can make an informed choice when given options.
- Individual knows that having intercourse or other sexual relations can result in obtaining a disease.
- Individual can differentiate between appropriate and inappropriate times and places to engage in intimate relations.
- Individual can recognise individuals or situations which might be a threat to him or her.
- Individual will stop behaviour if another person tells him or her 'no'.

Meanwhile, the authors found that, in general, knowledge related to pregnancy, sexually transmitted diseases, basic gender differences, sexual conduct and personal safety were rated as most important, while biological issues (such as the meaning of ovulation, impotence, menopause) and moral issues were rated as far less important (Kennedy & Niederbuhl, 2001).

3.7 Critique of models of capacity assessment

McCarthy (2003: 38) has critiqued models of capacity assessment in relation to consent to sexual activity, which focus on assessing an individual's ability to give consent and the conditions which need to be in place: capacity (the aptitude to acquire knowledge) and information (weighing up the pros and cons of a decision). She argues that such approaches tend to look at individuals at specific moments in time and not at the overall social context in which they are placed. Little attention is paid to gender-based inequalities in peer and intimate relationships. From her experiences of working with women with learning difficulties she concluded that in many cases the women's ability to give free and informed consent to sex had been compromised by some particular factors that had to do with their learning difficulties, but also by factors that had to do with their being women in unequal relationships with men.

Benedet & Grant (2007), meanwhile, argue for rethinking capacity to consent under its current binary definition (i.e. the complainant can consent to all sexual activity or none at all). They note that the issue of capacity to consent rarely arises in sexual assault cases in Canada and that it is rarely argued by the Crown or addressed in anything more than a passing reference by trial judges. It is assumed in the majority of sexual assault cases that the adult complainant is capable of giving consent, unless there is evidence of mental disability. Expert evidence may be given in such cases but it is not required. Benedet and Grant (2007) contend that rather than assessing capacity on a situational basis, judges tend to treat capacity as a static and absolute condition: one is capable of consenting to any sexual activity or to none at all.

Similarly, Stavis and Walker-Hirsch (1999), writing in the US context, suggest that it is incorrect to consider capacity to consent to sexual activity as an all-or-nothing ability. Instead, they argue, some activities

require very little understanding or regulation (apart from mutual consent), whereas others (e.g. sexual intercourse) require assessment of capacity according to state laws.

In relation to sexual assault cases, it has been argued that the capacity inquiry overly focuses on the 'defects' of the complainant rather than on the coercive behaviour of the accused (Benedet and Grant, 2007: 287). Benedet and Grant contend that a problem with US case law is that the inquiry into the nature of a woman's disability and associated mental capacity can prevent any inquiry into whether there was evidence of non consent. In some cases, evidence of force and non consent is ignored; once the complainant is deemed capable, the accused is acquitted, since non consent is not an element of the special offence (Benedet and Grant, 2007). Similarly, Wacker et al. (2008), writing in the US context, argue that most states' sexual assault legislation relating to adults with cognitive disabilities overly concentrates on the victim's capacity to consent. Trials involving victims with mental impairments turn into 'an exhaustive evaluation of the victim's capabilities: the prosecution argues that victims were not intelligent enough to consent, and the defense argues that victims were not impaired enough to invalidate their consent' (2008: 88).

Benedet and Grant (2007) contend that US law may have developed this focus on incapacity because the understanding of non consent in that country has not advanced to the level expressed in the Canadian case of R v Ewanchuk [64], but rather still requires proof of a clear expression of resistance in the face of force before reaching a finding of rape. R. v Ewanchuk confirmed that mere compliance does not amount to consent and that there must be some positive evidence of consent. Benedet and Grant (2007) observed that consent, therefore, cannot be implied from silence, passivity, or ambiguous behaviour, because it is the complainant's state of mind that is at issue. They note that this is important for women with mental disabilities as it is typical in these cases to see compliance in sexual activity along with no real evidence of affirmative consent.

64 R v Ewanchuk [1999] 1 S.C.R. 330 at para. 23, D.L.R. (4th) 193.

3.8 Situational aspect of capacity

Murphy & O'Callagahan (2004) make the point that capacity to consent to sexual relationships is not a static phenomenon. Niederbuhl and Morris (1993) maintain that the situational aspect of assessment of capacity could also be applied to the area of sexual relationships. That is, an individual may be capable of consenting to some forms of sexual contact with a certain individual in a particular setting but not to other forms of sexual contact with the same, or other, individuals in other settings (1993: 305).

Benedet and Grant (2007) note that there may be differences in capacity depending on the nature of the relationship between the accused and the complainant, particularly where the accused is in a relationship of trust with, or position of authority over, the complainant. For example, a woman with intellectual disability may be capable of consenting to sex with her boyfriend but not with her doctor. The point is made that decision-making is contextual, and that once a person is deemed as incapable of consenting, her/his opportunities for sexual expression can become limited due to the global nature of the determination. Niederbuhl and Morris (1993) propose that situational capability is one way of striking a balance between enhancing individual self-expression while ensuring that the individuals are not being exposed to undue risk.

3.9 Level of disability and capacity to consent to sexual relationships

Benedet & Grant (2007) contend that a more nuanced assessment of capacity might also consider the nature of the sexual acts involved and the degree of risk associated with them. Kaeser (1992) notes, for example, that an individual with a moderate to severe intellectual disability who resides in a residential facility might be able, through targeted sexual education and assistance from staff, to consent to sexual activity with a fellow resident. That same person, though, might not have the capacity to consent to sexual activity with a stranger who is visiting the facility. Ames and Samowitz (1995) and Kaeser (1992) assert that some persons who function in the severe to profound ranges of intellectual disabilities, who are unable to verbally demonstrate the necessary rationality and knowledge, are capable of sexual consent. Ames and Samowitz (1995) have suggested the following criteria for inferring capacity to consent to sexual relationships: voluntariness;

safety; no exploitation; no abuse; ability to say 'no'; and socially appropriate time and place.

Ames and Samowitz assert that it is critical for the residential provider agency to provide adequate supervision and guidance to the individuals so as to ensure continued monitoring of an individual's responsible sexual behaviour and consent. Kaeser (1992) argues that if individuals with severe intellectual disabilities show by their behaviour that they wish to engage in certain forms of sexual contact, and if the care team considers that this contact could improve the quality of the individuals' lives, then third-party consent should be sought, the same as it is in other matters judged to be in a person's best interests.

3.10 Protective legislation

McCarthy (1999) stresses that acknowledging the vulnerability of people with intellectual disability in a legal sense may contribute towards changing public opinion, which is either ignorant about the lives of individuals with intellectual disability, or unaware of their existence. The very real need to provide adequate protection to people who may be in vulnerable circumstances cannot be overstated; states have therefore enacted various laws providing different levels of protection to adults with intellectual disability at risk.

In most countries there exists the presumption of capacity and a principle of autonomy which is provided for typically in human rights legislation (Europe) and in the Bill of Rights (US). The following discussion presents the main ways in which perpetrators of sexual crimes against people with learning disabilities can be prosecuted (framework adapted from McCarthy & Thompson, 2004):

- Laws that prohibit sex with people deemed unable to consent to sex
- Laws that incorporate a functional approach to assessment of capacity to consent to sex
- Generic laws applying to sex without consent
- Laws that prohibit specific sexual relationships.

3.11 Laws that prohibit sex with people deemed unable to consent to sex

McCarthy & Thompson (2004) note that the basis of laws that prohibit sex with people deemed unable to consent to sex is that some people are so disabled that they are unable to give consent to any sexual relationship. Individuals may be judged as being incapable of consenting to any sexual relationship because they are identified as having either general deficits in understanding or specific deficits concerning sexual knowledge (McCarthy & Thompson, 2004). McCarthy & Thompson (2004) suggest that in Ireland Section 5 of the Criminal Law (Sexual Offences) Act 1993 is an example of a diagnostic approach to consent, where a person's capacity to make a specific decision is deemed inadequate because they have a certain level of learning disability.

3.11.1 The Criminal Law (Sexual Offences) Act 1993

The Criminal Law (Sexual Offences) Act 1993 changed the law governing offences against people with intellectual disabilities in Ireland. Prior to this the only statutory prohibition of the sexual exploitation of people with intellectual disability was in Section 4 of the Criminal Law Amendment Act 1935, which used outdated terminology and whose principle aim was the protection of 'mentally impaired' women from sexual intercourse. The main objective of this Act, as O'Malley suggests, was the prevention of unwanted pregnancies (O'Malley, 1996).

Section 5 of the Criminal Law (Sexual Offences) Act 1993 makes it illegal to have sex with people 'with a disorder of the mind, whether through mental handicap or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life or of guarding against serious exploitation' unless they are married to each other. A defence is available to a person who did not know and had no reason to suspect that the person was 'mentally impaired'. It may be difficult to prove that a man is guilty of sexually offending a 'mentally impaired' person because the alleged perpetrator could use in his defence that he did not know and had no reason to suspect that the 'victim' was mentally impaired.

3.11.2 Criminalising sexual activity between persons with an intellectual disability

In its report on sexual offences, the Law Reform Commission (LRC, 1990) recognised that a sexual relationship between persons with mental handicap or mental illness should not of itself constitute an offence. However, this proposal was not included in the subsequent legislation, the 1993 Act. Therefore, it is an offence to engage in sexual activity with a person with an intellectual disability (that comes within the definition of mental impairment), even if the person consents.

The Law Reform Commission (LRC 2005) noted that a regrettable effect of Section 5 of the 1993 Act is that outside a marriage context a sexual relationship between two 'mentally impaired' persons may constitute a criminal offence because there is no provision for consent as a defence in respect of a relationship between adults who were both capable of giving a real consent to sexual intercourse (McAuley and McCutcheon, 2000: 515). The law, therefore, effectively blocks a mutually consensual sexual relationship between persons considered to have a limited decision-making ability. Similarly, Graydon et al. (2006) have been critical of the protective nature of Section 5 of the 1993 Act for the fact that outside of a marriage context it is an offence for any person to have sexual relations with a person incapable of protecting themselves against sexual exploitation.

It has been argued that if sexual development and reproduction are to be possible, it must be legally acceptable for people with a 'mental handicap' to enter into sexual relationships. [65] In this regard, the Law Reform Commission notes that fear of facilitating the commission of a criminal offence on the part of parents and carers may prevent relationships between two adults with intellectual disability developing even where they have capacity to consent and there is no element of exploitation (LRC, 2005: 142).

O'Malley (1996: 133) has commented that the criminal law has a limited capacity to achieve a balance between protection and sexual

65 Gunn Medical Law (1986) 255 at 257. Quoted in Law Reform Commission Report on Sexual Offences Against the Mentally Handicapped (LRC, 1990) at paragraph 12.

autonomy and fulfilment. In commenting on Section 5 of the 1993 Act he considered:

> Unless complemented with other guarantees to maximise individual freedom of choice, it [Section 5 of the 1993 Act] may swing the balance too far in the direction of depriving mentally ill or disabled persons of the right to a sexual life compatible with their physical, mental and emotional capacities ... the section fails to reflect the rights of persons who are mentally impaired to have a sexual life. (O'Malley, 1996: 133)

3.11.3 Finding an appropriate definition of intellectual disability in the context of capacity to consent to sexual relations

It is recognised that one of the main difficulties in drafting legislation in this area is finding an appropriate definition of intellectual disability. In Ireland The Law Reform Commission has commented that both the concept and definition of 'mentally impaired' is unsatisfactory: the term 'mentally impaired' itself can be considered objectionable and stigmatising and, secondly, the test of ability to guard against serious exploitation (the second test in Section 5 (5) of the 1993 Act) was considered to be a better yardstick of capacity to consent rather than ability to lead an independent life (the first test in Section 5 (5) of the Act) (LRC, 2005). This viewpoint has been reiterated by Namhi (now Inclusion Ireland), who note that the criterion of being incapable of guarding against serious exploitation was a better one. They add that there are many people with intellectual disabilities who are not capable of leading an independent life but who are capable of guarding against serious exploitation (Namhi 2003).

The Law Reform Commission was of the view that if the matter arose for consideration, Section 5 of the 1993 Act may be considered to breach Article 8 of the ECHR by disproportionately interfering with a person's right to respect for his private life. The Commission stated that an option for reform would be to amend Section 5 of the 1993 Act, drawing on the functional approach adopted in England and Wales in relation to the Sexual Offences Act 2003 (LRC, 2005). In concluding, the Law Reform Commission (2005) stated that it was clear that this is a complex area where law and society's views are not settled and found it appropriate to invite views on reform in the area.

Submissions received by the Law Reform Commission on its Consultation Paper (LRC, 2005) highlighted the fact that Section 5 of the 1993 Act should be expanded to include all forms of unwanted sexual contact rather than being confined to attempted and actual sexual intercourse, buggery and acts of gross indecency between males.

3.11.4 Other jurisdictions using diagnostic criteria

In England and Wales there was a diagnostic criterion in place in the Sexual Offences Act, 1956 & 1967 in that people with severe intellectual disabilities were considered not able to consent in law, i.e. it was not lawful to have sex with someone who was a 'mental defective' or had 'severe mental handicap' (Gunn, 1996; Gunn, Bellhouse, Clare, Holland and Watson, 2001).

Western Australia

The Western Australian Criminal Code, S. 330 (1) contains a similar provision to that contained in Section 5 of the 1993 Act, with a reference to an incapable person being one who is incapable of understanding the nature of the sexual act, or of protecting themselves against sexual exploitation. Any sexual act with such a person may be the subject of a charge under the legislation (Graydon, Hall and O'Brien Malone, 2006: 160).

United States

Wacker et al. (2008) note that forty-five states in America specify that individuals with so-called mental deficiencies [66] are incapable of legally consenting to a sexual act (Sexual Assault Statutes, 2006). According to Benedet & Grant (2007) the threshold for incapacity seems to be much higher in the United States (compared to Canada), where there have been high conviction rates of men who have exploited people with intellectual disability and where complainants are routinely found to be incapable of consent. The authors note that most US state penal statutes have a provision that explicitly criminalises sexual activity with women labelled as mentally disabled. Wacker et al. (2008) reported that state

66 States typically define mental deficiencies to include developmental disabilities and mental retardation.

laws generally require that courts determine three factors in assessing a victim's capacity to consent:

- Knowledge of relevant facts
  Victim's awareness of the nature and consequences of sexual activity, which can be interpreted by the courts either narrowly (basic understanding of the physiological aspects of sexual contact) or broadly (awareness of the moral, ethical, and emotional dimensions of sexual contact).

- Intellectual ability
  Evaluation of the victim's ability to comprehend and rationally evaluate the risks and benefits of engaging in sexual activity.

- Voluntariness
  Assessment of the victim's vulnerability to coercion and level of understanding of the fact that she may choose to engage in or refrain from sexual activity (Reed, 1997; Stavis, 1991).

The lowest threshold for capacity is evident for New Jersey, where in order to be capable of providing consent, the complainant only needs to know the physical nature of the sexual act and that she has the right to refuse it. At the other extreme, courts in seven states, [67] including New York, have held that the complainant must not only understand the physiological aspects of sex, but also be able to consider its potential consequences, (such as pregnancy or sexually transmitted diseases) and the moral dimension of choosing to engage in sexual activity (Benedet and Grant, 2007). In one Canadian case, R v A.A. (2001), [68] which dealt with the issue of capacity, a test similar to the middle ground prevailing in most US states was adopted, which is that the complainant understands the physiological aspects of sex as well as its potential consequences of pregnancy and disease transmission (Benedet and Grant, 2007). However, in addition, the trial judge in the case recognised that capacity includes an understanding of the absolute right to choose

67 Highest threshold states include Alabama, Colorado, Hawaii, Idaho, Illinois, New York, and Washington. Denno, D.W. (1997) 'Sexuality, Rape, and Mental Retardation' University of Illinois Law Review. 315.

68 R. v. A.A. (2001), 144 O.A.C. 382, 155 C.C.C. (3d) 279, 43 C.R. (5th) 272 [A.A.].

whether or not to engage in sexual activity, which according to Benedet and Grant (2007) can often be overlooked by courts.

3.12 Laws that incorporate a functional approach to assessment of capacity to consent

The alternative to the diagnostic approach is the functional approach, where a person's capacity to consent is judged on the basis of their ability to understand information relating to the matter in hand. This approach is favoured by the Law Reform Commission: they recommended that an adult's legal capacity is assessed in relation to the particular decision to be made at the time it is to be made, i.e. capacity should be issue-specific and time-specific (LRC, 2005). According to McCarthy & Thompson (2004), writing in the context of the UK, the critical question is the level of knowledge and skills that is required for a person to be able to consent to sex. It is also important to appreciate that where a person with a mental disorder is able to consent freely to sexual activity they have the same rights to engage in consensual sexual activity as anyone else. [69]

3.12.1 Sexual Offences Act 2003, England and Wales

The Sexual Offences Act 2003 in England and Wales defined capacity to consent to sexual relationships in terms of ability to refuse. The Act creates three sets of offences where the complainant is a person with a mental disorder [70] (which includes a learning disability) (Stevenson, Davies and Gunn, 2004). These are:

- Offences concerned with sexual activity involving a person with a mental disorder; these apply where the person cannot consent to the sexual activity (Sections 30 – 33).

- Offences where the person's agreement to engage in sexual activity is secured through an inducement, threat or deception (Sections 34 – 37).

69 Guidance on Part 1 of the Sexual Offences Act, 2003 accessed in December 2008 at www.homeoffice.gov.uk/ about-us/publications/home-office-circulars/ circulars-2004/021-2004.

70 Mental disorder is defined as "mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind". This definition includes "learning disability".

- Offences where the defendant is in some form of care relationship with the complainant; these offences may be committed regardless of consent (Sections 38 – 41 (discussed below)).

A person is unable to refuse if she 'lacks the capacity to choose whether to agree to the touching (whether because she/he lacks sufficient understanding of the nature or reasonably foreseeable consequences of what is being done or any other reason)' or is unable to communicate such a choice. [71] Capacity to consent is articulated in terms of functional capacity (and not by a diagnostic or status approach) to understand the nature and consequences of the act and a person with a mental disorder's ability to communicate his/her choice.

Sufficient understanding of the nature and reasonably foreseeable consequences might include knowing that sexual activity is different from personal care and that some sexual activities can lead to pregnancy or the transmission of disease. Other reasons why a person may be unable to refuse might include not understanding that they had a choice through institutionalisation, or because they suffered from a condition that might affect the ability to make a choice. [72]

It is a requirement of the offences under Sections 30 – 33 that the offender knew or could reasonably have been expected to know that because of a mental disorder the person was likely to be unable to refuse.

The Sexual Offences Act 2003 introduces a new offence of 'obtaining sexual activity by inducement, threat or deception with a person who has a learning disability or mental disorder'. This offence is aimed at individuals who both deliberately and repeatedly target people with learning disabilities because of their vulnerability to sexual exploitation (McCarthy and Thompson, 2004). In these offences there is no need to prove that the 'victim' is unable to refuse. This offence is intended to protect individuals with learning disabilities who with other people

71 Section 30 of the Sexual Offences Act 2003.

72 Guidance on Part 1 of the Sexual Offences Act, 2003.

would be considered able to give their consent to a sexual relationship. In this regard, McCarthy & Thompson (2004: 238) suggest that it is an example of a positive development towards striking a balance between sexual rights for people with learning disabilities and protection from exploitation.

3.12.2 Other jurisdictions

In most states in Australia, the knowledge required for legal consent to a sexual act is only that the person understands the nature of the act (Graydon, 2006) but there is no need to know the consequences. [73] This decision of the Supreme Court of Victoria, in the case of Morgan (1970, VR 337) represents a less stringent test (where consideration of the consequences of sexual acts appears to have been excluded). It must be proved that the person does not have sufficient knowledge or understanding to comprehend either that sex may involve physical penetration of the body or that penetration is an act of sexual connection, as distinct from an act of a totally different character. According to the Victorian Law Reform Commission (2001) using this standard most people with impaired mental functioning will be capable of consenting to sexual activity. The Morgan standard is lower than that of most American states, which require understanding of the nature and consequences of the act (Sundram and Stavis, 1994).

The Morgan direction was elaborated upon in R v Mueller (2005), another case in which it was alleged that the complainant lacked capacity to consent. The jury was directed that it was sufficient if the 'complainant has knowledge or understanding of what the act comprises, and of its character ... then she has all that the law requires for capacity to consent (Graydon, 2006).

An advantage of retaining the Morgan standard is that the sexual autonomy of persons with intellectual disability would be preserved. Research has demonstrated that only about half the population with intellectual disability (in studies carried out in the UK and Australia) reported having ever received sex education (O'Callaghan & Murphy,

73 The sole exception is South Australia, where the nature and consequences of the act must be understood (Criminal Law Consolidation Act 1935 S. 49).

2002; McCabe, 1999). Graydon (2006) contends that there may be a relationship between the level of sexual knowledge and the incidence of sexual assault (referring to research among people with mild cognitive impairment (McCabe, 1992) and thus the provision of sex education may not only be an effective means of increasing knowledge, but may also fulfil a protective function.

On the other hand, McSherry (1998) argues that the advantage of increasing the standard to knowledge of the consequences of sexual activity is that it would likely lead to more convictions in that, for example, where understanding of the relationship between sex and pregnancy could not be established, the prosecution's task of proving incapacity would be an easier one. Graydon (2006) asserts that a woman who is unaware of the relationship between sex and pregnancy may be exposing herself to a number of risks, not least to her own health and well-being. Graydon goes on to state that the serious consequences of sex warrant that an understanding of the nature and consequences of the act should underlie a valid consent. She makes the case for a more stringent test of capacity combined with adequate sex education: 'For people who currently do not understand the consequences of sex but who would be able to acquire that knowledge given appropriate education, introduction of a more stringent standard of knowledge would actually support autonomous decision-making.' (Graydon, 2006:7)

3.13 Generic laws applying to sex without consent

Cases of capacity to consent to or refuse sexual relationships for people with learning disabilities typically arise as part of an allegation of sexual assault. The criminal law is intended to deter abuse by prosecuting and punishing those who seek to take advantage of vulnerable people. Where there is sexual activity and consent is disputed, an offence (such as rape or indecent assault) may have taken place. An offender who rapes or assaults a person with an intellectual disability can be prosecuted for rape or indecent assault. Where one person touches another person in a sexual manner without the other person's consent, a sexual assault or aggravated sexual assault [74] may have been committed. Where a person has penetrative sexual relations with a person over the age of

74 See Section 2 and Section 3 of the Criminal Law (Rape) (Amendment) Act, 1990.

consent who lacks the mental capacity to consent, this may amount to rape, where the person knows or is reckless as to whether the other person consents. [75]

In Ireland the Law Reform Commission (LRC, 2005) notes that 'consent' is not defined in legislation dealing with rape or sexual assault but its existence is to be objectively determined. In relation to a sexual assault offence, however, the law in Ireland provides that submission without resistance will not in itself amount to evidence that there was consent (Section 9 of the Criminal Law (Rape) (Amendment) Act 1990) (LRC, 2005). Case law has demonstrated that a person will not have the capacity to consent if they do not understand the nature and consequences of the act (LRC, 2005: 136). McCarthy (1999), as noted earlier, pointed out the problem with rape and sexual assault laws designed to relate to adults without learning disabilities is that they may not consider the limited capabilities and pressures that adults with learning disabilities may face.

3.14 Laws that prohibit specific sexual relationships

According to McCarthy and Thompson (1997), it is not uncommon for members of staff to sexually abuse the people they are paid to care for, although there is evidence to suggest that this is one of the most difficult forms of sexual abuse for people with learning disabilities to disclose. McCarthy and Thompson highlight the fact that staff rarely need to employ force, as many people with learning disabilities will comply with the request or demands of those in authority out of habit, fear, confusion or lack of understanding of what is happening (2004: 231). The authors assert that the specific power held by people in positions of authority should not be interpreted as evidence of the willing participation of the person with learning disabilities. This specific power undermines the potential for free consent (McCarthy & Thompson, 2004).

McCarthy and Thompson (2004) note that because of the difficulty of providing a valid and reliable working definition of informed consent, legislation that avoids tests of consent is attractive and may lead to

75 Rape offences are covered under Section 2 of the Criminal Law (Rape) (Amendment) Act 1981 (as amended) and Section 4 of the Criminal Law (Rape) (Amendment) Act 1990.

higher prosecution rates. In relation to people holding positions of power, Graydon et al. (2006) have argued that using a capacity-based definition may make it more difficult to prosecute offenders. For example, the Victorian Law Reform Commission, in their final report on sexual offences (VLRC, 2004), considered that, in relation to sexual offences committed by health professionals and workers in a residential facility, [76] a definition which was solely based on capacity would make the offence more difficult and lengthy to prosecute. They argued that a capacity-based definition could result in a wide range of experts being called to testify about whether or not the complainant had the capacity to make a choice about whether or not to participate in sexual acts with people in positions of power over her. If experts presented conflicting opinions on whether or not the person had capacity to make an informed choice to participate in sexual acts, a situation could arise where a jury might not convict an accused who claimed that he believed the complainant had made such a choice. Therefore, they recommended that a capacity-based definition should not be adopted in relation to these offences.

In England and Wales there is protective legislation for adults with intellectual disabilities with regard to their care relationships. Sections 38-41 of the Sexual Offences Act, 2003 deal with the situation where a care worker involves someone in his care who has a mental disorder in sexual activity. In these offences any sexual activity between the care worker and the person with the mental disorder is prohibited whilst that relationship continues. Where it is proved that the other person had a mental disorder, it is to be taken that the defendant knew or could reasonably have been expected to know that the person had a mental disorder, unless sufficient evidence is produced to show the contrary. In that case, the prosecution must prove that the offender knew or it was reasonable to expect them to have known that the other person had a mental disorder.

A care worker can include not only doctors, nurses and social workers but also receptionists, cleaning staff, advocates or voluntary helpers. [77]

76 Sections 51 and 52 of the Crimes Act 1958, as amended by the Crimes (Sexual Offences) Act 2005, discussed below.

77 Guidance on Part 1 of the Sexual Offences Act, 2003.

Subsections (2) to (4) describe the circumstances in which a relationship of care exists.

Other jurisdictions which have sought to legally limit sexual contact between staff and the people they are paid to support include the Netherlands, Germany, some states in the US (McCarthy & Thompson, 2004) and the state of Victoria, in Australia (VLRC, 2001).

In Victoria, Australia, Sections 51 and 52 of the Crimes Act 1958 specify an appropriate standard of behaviour for those providing services to people with a cognitive impairment. The Victorian Law Reform Commission (VLRC, 2004) recommended a number of amendments to these sections; these were adopted in the Crimes (Sexual Offences), Act 2006. The term 'cognitive impairment' replaced 'impaired mental functioning', which includes impairment because of mental illness, intellectual disability, dementia or brain injury [Section 15 (a)].

Section 16 of the Crimes (Sexual Offences) Act 2006 makes it an offence for a person who provides medical or therapeutic services to a person with cognitive impairment who is not his or her spouse or domestic partner to engage in an act of sexual penetration with that person (Section 16 (1)) or to commit or be in any way a party to the commission of an indecent act with that person (Section16 (2)). In circumstances where the services provided by the accused were related to the cognitive impairment of the other person, a defence is available where the accused believed on reasonable grounds that the other person did not have a cognitive impairment (Section 16 (3)). This is to cover the rare situation where a person providing services relating to the impairment is not aware that the person had a cognitive impairment (VLRC, 2004: 336).

Section 16 (4) creates an offence in which the services provided by the accused were not related to the cognitive impairment of the other person; in these circumstances a defence is available to the accused where he/she was not aware that the other person had a cognitive impairment. These service providers (e.g. a dentist, a chiropractor) will only be guilty of the offence if they were aware of the impairment (VLRC, 2004: 336).

Section 17 of the Crimes (Sexual Offences) Act 2006 covers offences against residents of residential facilities. It is an offence for a worker at a facility to take part in an act of sexual penetration with a person with cognitive impairment, or to commit or to be in any way party to the commission of an indecent act with a person with a cognitive impairment who is residing in the facility or attending the facility to take part in a programme, and who is not his or her spouse or domestic partner.

The Victorian Law Reform Commission's final report on sexual offences (2004) discussed the issue of allowing a defence of consent, with the onus on the accused to demonstrate that consent was not obtained through the abuse of trust or professional authority. The authors considered that the defence of consent would be inconsistent with the policy goal of protecting people with cognitive impairment from exploitation through these offences. They argued that allowing a defence of consent in these circumstances would invariably raise the issue of capacity, which would lead to difficulties in prosecution, as discussed earlier. They did not therefore recommend adopting a capacity definition for the purpose of these offences, which apply regardless of whether the complainant consented to taking part in sexual activities.

In Canada, Section 153.1 of the Criminal Code makes it an offence to have sexual contact with a person with a disability in circumstances in which there is a relationship of authority or dependency between the accused and the person with a disability, and where the person with the disability does not consent to the contact (Benedet & Grant, 2007). Consent means the voluntary agreement of the complainant to engage in the sexual activity in question. Proof of non consent is required. The provision has rarely been used since its introduction, a fact the authors argue is related to trying to satisfy the dual goals of protection from harm and the promotion of sexual autonomy in contradictory ways. The authors argue that Section 153.1 does nothing to add to this area of law, as the crime of sexual assault already criminalises sex without consent, without requiring proof of 'disability' and one of the listed power relationships. If Section 153.1 had simply criminalised sex with a person with a disability where one of the specified power relationships existed it would, they argue, have added something to the law on sexual offences (Benedet & Grant, 2007).

McCarthy and Thompson (2004) note that even where a person with an intellectual disability is in a relationship with a staff member that may be viewed as sexually exploitative by others, that person may be unhappy when an intervention is taken to end the relationship. The reason for this, they note, is that although the sexual side of the relationship is likely to be exploitative and may be experienced as physically painful, people with learning disabilities often take a wider view by valuing the presence of that person in their life and the attention they receive (2004: 232). McCarthy and Thompson argue that a broad concern about the welfare of people with learning disabilities needs to consider not only the damage done to them in such relationships, but also the damage done by ending such relationships.

3.15 Provision of supports

Brown (2004) argues that from a rights perspective, the argument of supporting women to make their own choices, while retaining responsibility to consult and assist, or to step in to take proxy decisions when the woman is out of her depth is a strong one. Article 12 of the UN Convention on the Rights of Persons with Disabilities requires States Parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. In particular, Article 23 1 (b) of the Convention recognises the rights of persons with disabilities to have access to age-appropriate information, reproductive and family-planning education and the means necessary to enable them to exercise their rights to marry and found a family.

In Ireland, the Law Reform Commission has emphasised the close connection between the promotion of capacity to consent to sexual relationships and the provision of sex education to young adults with limited decision-making ability which is pitched at an appropriate level to their capacity (LRC, 2005: 145).

Research has shown that people with intellectual disability often have more limited sexual knowledge than other people (McCabe, 1999; Murphy and O'Callaghan, 2004) and are more vulnerable to abuse than others. Research carried out in England by Murphy and O'Callaghan (2004) has important implications for capacity to consent to sexual

relationships. The study involved 60 adults with intellectual disabilities (30 male and 30 female) and 60 young people without disabilities (30 male and 30 female). The main aim of the project was to assess sexual knowledge, vulnerability and capacity to consent to sexual relationships in adults with intellectual disabilities and to compare them with young people without disabilities (aged 16-17 years) presumed in law able to consent to sexual relationships.

Attempts to operationalise the definition of capacity using the UK's Foundation for Learning Disabilities' criteria [78] suggested that about half of the people involved in this research project would have been unable to consent to sexual relationships because they did not understand about pregnancy and/or sexually transmitted diseases (Murphy and O'Callaghan, 2004).

Findings demonstrated that levels of sexual knowledge for adults with intellectual disabilities (mild to moderate) were far lower than for non-disabled 16 to 17 year olds. Adults with intellectual disability often lacked knowledge in a number of key areas, including pregnancy, masturbation, contraception, birth control, sexually transmitted diseases, types of sexual relationships and legal aspects of sex. In relation to pregnancy, one-third of the adults with learning disabilities did not know how pregnancy occurred; 50 per cent did not know what a condom was for and 60 per cent did not know about HIV/AIDS. There were no gender differences in the findings.

Reasons for these findings were that adults with intellectual disability had had less sex education than the other young people; they may also have had less informal sex education (from peers and/or from magazines) and/or information from parents, fewer girlfriend/boyfriend relationships and thus fewer sexual experiences than the young people (O'Callaghan and Murphy, 2002).

The project found that people who had had sex education were more knowledgeable and less vulnerable than those who had not. They

78 (1) That sex is different from personal care, (2) That penetrative vaginal sex can lead to pregnancy, (3) That penetrative anal sex is associated with a risk of HIV/AIDS.

concluded that it was essential for people to have on-going access to sex education (as opposed to the 'one-shot' variety), particularly with regard to sexual health and pregnancy, contraception, safe sex, abuse, and some aspects of the law (such as consent).

3.16 Guidelines

Murphy and Clare (2003:47) note that in the UK context, local policy guidelines on personal and sexual relationships and adult protection procedures have been drawn up by and for staff in residential and day care facilities for vulnerable people (e.g. Brown and Stein, 1998), and by UK state bodies (Department of Health, 2000; ADSS, 2005). Murphy and Clare (2003) emphasise that the majority of guidelines are mainly concerned with procedures to be followed when abuse comes to light, and tend not to provide guidance on what constitutes consent.

Table 3: Comparative legislation – sexual offences and intellectual disability (This is illustrative, rather than an authoritative statement of the law.)

Legal aspect	Ireland	United Kingdom	Australia
Relevant legislation	Section 5 of the Criminal Law (Sexual Offences) Act 1993	Sections 30 – 33 of the Sexual Offences Act 2003	Common law – benchmark established - Crimes Act 1900 (ACT) s 92P (1) (i); Criminal Code (NT) s 192(2)(d); Criminal Law Consolidation Act 1935 (SA) s 49 (6); Criminal Code (Tas) s 2A (2) (c); Crimes Act 1958 s 36 (e)
Main features	Where a person has or attempts to have sex* with a person who is 'mentally impaired' unless they are married to each other	An offender must have known, or be reasonably expected to have known that the victim had a mental disorder, and that because of that disorder the victim was unlikely to be able to refuse Offence created if sexual activity occurs with a person with a mental disorder who 'lacks the	Five Australian jurisdictions state that there is no consent where an individual is 'incapable of understanding' the sexual nature of the act. In South Australia, an understanding of the 'nature or consequences'** of sexual intercourse is required. (McSherry, 1998)

* Sexual intercourse or buggery.

** Criminal Law Consolidation Act 1935 (SA) Section 49 (6).

Legal aspect	Ireland	United Kingdom	Australia
Main features (continued)		capacity to choose whether to agree to the touching, whether because she/he: -lacks sufficient understanding of the nature or reasonably foreseeable consequences of what is being done -or for any other reason -or they are unable to communicate such a choice Offences also created where a person with mental disorder is coerced into sexual activity by inducement, threat or deception	**R v Morgan** (1970) case: It must be shown that a person does not have sufficient knowledge or understanding to comprehend: a) That what is proposed to be done is the physical fact of penetration of her body by the male organ or, if that is not proved b) that the act of penetration proposed is one of sexual connection as distinct from one of totally different character

Legal aspect	Ireland	United Kingdom	Australia
Termin-ology used	Mentally impaired means: ‘‘a disorder of the mind, whether through mental handicap or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life or of guarding against serious exploitation.	Mental disorder is defined as “mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind”. This definition includes “learning disability”	

Legal aspect	Ireland	United Kingdom	Australia
Test of capacity	Diagnostic approach fulfilling a protective function; a person lacks capacity if she/he cannot lead an independent life or guard against serious exploitation	Functional concept of lack of capacity to consent in relation to persons with a mental disorder involving an absence of 'sufficient understanding of the nature of the act and reasonably foreseeable consequences'* or an inability to communicate choice; considered to be a less stringent test and therefore, provides more autonomy	Functional approach; lower standard of knowledge than is necessary for informed consent to therapeutic treatment and also lower than most American states (Graydon, 2006)

* Includes knowing sex is different from personal care and can lead to pregnancy and to sexually transmitted diseases.

Legal aspect	Canada	United States of America
Relevant legislation	Section 153.1 of the Canadian Criminal Code	Threshold for capacity to consent varies from state to state
Main features	Creates an offence of sexual exploitation of a person with a mental disability in circumstances in which there is a relationship of trust or authority between the accused and the person with a disability and where that person does not consent to the contact	
Termin-ology used	The term 'disability' is not defined. 'Consent' has the same definition as for sexual assault generally	
Test of capacity	Section 153.1 has rarely been used since its enactment	Diagnostic approach in the majority of states; test of capacity varies but in general the complainant must understand the physiological aspects of sex as well as its potential consequences of pregnancy and disease transmission

3.17 Key findings

The key findings from the review of literature in the area of capacity to consent to sexual relationships are presented below:

Capacity to consent to sexual relationships

- A finding that a person lacks capacity results in a restriction or removal of fundamental human rights and therefore the issues of capacity and rights are inextricably linked (LRC, 2005).

- There has been far less consideration of capacity in the context of consenting to sexual relationships (Murphy, 2003).

- The difficulty in designing legislation that would provide for a balance between the need to protect vulnerable individuals from exploitation and the need to respect an individual's autonomy and capacity to engage in voluntary and freely chosen relationships has been recognised (LRC, 2005).

- In relation to sexual violence and exploitation research consistently shows that women with learning disabilities are at risk from abuse, predominantly by men within their networks, including other service users, staff, family members, neighbours and friends of the family.

- Definitions of abuse highlight ability to consent as well as potential inequalities of power between the 'victim' and the accused, in particular there may exist 'barriers' to consent within certain relationships (Brown and Turk, 1992).

- It has been argued that a model of capacity should both maximise the woman's involvement in decision-making and, when it comes to serious abuses, help her to seek refuge, justice and redress (Brown, 2004).

- Deciding to enter into a sexual relationship with another individual is a personal decision which does not generally require

any formal contract or test of capacity (BMA and the Law Society, 2004).

- Legislation on mental capacity in England and Wales, the Mental Capacity Act 2005, does not cover people who lack capacity to consent to have sexual relations as it was considered that such a decision was so personal to the individual concerned that it could not be made on behalf of a person.

Approaches to determining capacity

- The question of whether the law should impose a greater level of understanding than the simple fact of understanding the sex act has been examined. A higher standard, that of understanding the sexual act and its consequences, such as pregnancy and the risk of contracting sexually transmitted diseases might restrict the ability of many intellectually disabled adults to consent but would provide a higher degree of protection for potentially vulnerable adults (Evans and Rodgers, 2000).

- Models of capacity assessment which focus on assessing an individual's ability to give consent and the conditions that need to be in place: capacity (the aptitude to acquire knowledge) and information (weighing up the pros and cons of a decision) have been criticised (McCarthy, 2003). These models tend to look at individuals at specific moments in time and not at the overall social context in which they are placed.

- From McCarthy's (2003) experiences of working with women with learning disabilities, in many cases the women's ability to give free and informed consent to sex has been compromised by some particular factors which have to do with their learning difficulties and also factors which have to do with their being women in unequal relationships with men.

- Benedet and Grant (2007) argue for rethinking capacity to consent to sexual relations from its current definition i.e. the complainant can consent to all sexual activity or none at all. A finding of

incapacity should be specific to the task at hand; if incapacity is understood as a general condition, a finding of incapacity could result in criminalising all sexual relationships for that woman (Benedet & Grant, 2007).

- It has been argued that the situational aspect of capacity can be applied to sexual relationships, i.e. an individual may be capable of consenting to some forms of sexual contact with a certain individual in a particular setting but not to other forms of sexual contact with the same, or other, individuals in other settings (Niederbuhl and Morris, 1993).

- There may be differences in capacity depending on the nature of the relationship, particularly where the accused is in a relationship of trust with or position of authority over the complainant.

- US case law has been critiqued for overly focusing the inquiry on the nature of a woman's disability and associated mental capacity instead of gathering evidence of non consent (Benedet and Grant, 2007).

- Benedet and Grant (2007) observed that consent cannot be implied from silence, passivity, or ambiguous behaviour, because it is the complainant's state of mind that is at issue (R v Ewanchuk). They note that this is important for women with mental disabilities, as it is typical in these cases to see compliance in sexual activity along with no real evidence of affirmative consent.

Protective legislation

- Protective legislation can be analysed under the following framework: laws that prohibit sex with people deemed unable to consent to sex; laws that incorporate a functional approach to assessment of capacity to consent to sexual relations; generic laws applying to sex without consent; and laws that prohibit specific sexual relationships.

Laws that prohibit sex with people deemed unable to consent to sex

- Laws that prohibit sex with people deemed unable to consent to sex are based on the need to protect some people who are so disabled as to be unable to give consent to any sexual relationship. In Ireland Section 5 of the Criminal Law (Sexual Offences) Act 1993 falls under this category. Section 5 criminalises sexual activity with women who have a 'mental impairment', which is defined as rendering a person 'incapable of living an independent life or of guarding against serious exploitation' unless the two parties are married to each other. Thus, it may be an offence to engage in sexual activity with a person with an intellectual disability even if the person consents.

- It has been argued that if sexual development and reproduction are to be possible, it must be legally acceptable for people with a 'mental handicap' to enter into sexual relationships. [79] Fear of facilitating the commission of a criminal offence on the part of parents and carers may prevent relationships between two adults with intellectual disability developing even where they have capacity to consent and there is no element of exploitation (LRC, 2005).

- Other jurisdictions using diagnostic criteria in relation to capacity to consent to sexual relationships include Western Australia and forty-five states in the U.S.

Laws that incorporate a functional approach to assessment of capacity to consent to sexual relations

- The Sexual Offences Act 2003 in England and Wales provides an example of the functional approach, where capacity to consent is articulated in terms of a person's understanding of the nature and consequences of the act and her/his ability to communicate choice.

79 Gunn Medical Law (1986) 255 at 257. Quoted in Law Reform Commission Report on Sexual Offences Against the Mentally Handicapped (LRC, 1990) at paragraph 12.

- The Sexual Offences Act 2003 also introduces a new offence of 'obtaining sexual activity by inducement, threat or deception with a person who has a learning disability or mental disorder'. This is intended to protect individuals with learning disabilities who with other people would be considered able to give their consent to a sexual relationship. Thus it is an example of a positive development towards striking a balance between sexual rights for people with learning disabilities and protection from exploitation (McCarthy and Thompson, 2004).

- In most states of Australia the standard for capacity is low, where the knowledge required for legal consent to a sexual act is only that the person understands the nature of the act but there is no need to know the consequences (Graydon et al., 2006).

- Increasing the standard to an understanding of the consequences of the act would likely lead to more convictions, in that, for example, where understanding of the relationship between sex and pregnancy could not be established, the prosecution's task of proving incapacity would be an easier one. Retaining a lower standard (for example, the one set down in the Morgan case in Victoria, Australia) means that the sexual autonomy of people with intellectual disabilities is preserved.

- Graydon (2006) has argued that the serious consequences of sex warrant that an understanding of the nature and consequences of sex should underlie a valid consent. She makes the case for a more stringent test of capacity combined with adequate sex education.

Generic laws applying to sex without consent

- Where there is sexual activity and consent is disputed, an offence such as rape or sexual assault may have occurred and protection can be provided to women with intellectual disabilities under generic laws applying to sex without consent. It was noted that these laws are designed for adults without intellectual disabilities and may not take into consideration the limited capabilities

and the particular pressures faced by adults with intellectual disabilities (McCarthy, 1999).

Laws that prohibit specific sexual relationships

- It has been argued that the specific power held by people in positions in authority undermines the potential for free consent (McCarthy and Thompson, 2004). In recognition of this, laws have been created that avoid tests of capacity and consent and which may lead to higher prosecution rates (McCarthy and Thompson, 2004). In England and Wales, sections 38-41 of the Sexual Offences Act 2003 deal with offences where the defendant is in some form of care relationship with the complainant. In these offences any sexual activity between the care worker and the person with the mental disorder is prohibited whilst that relationship continues. Section 17 of the Crimes (Sexual Offences) Act 2006 in Victoria, Australia, provides another example of where it is an offence for a care worker to engage in an act of sexual penetration or to commit an indecent act with a person with a cognitive impairment.

Supports

- One study in the United Kingdom demonstrated that about half of the participants with intellectual disabilities involved in the research would have been unable to consent to sexual relationships because they did not understand about pregnancy and/or sexually transmitted diseases (Murphy and O'Callaghan, 2004). The authors concluded that it was essential for people to have on-going access to sex education (as opposed to the 'one shot' variety), particularly with regard to sexual health and pregnancy, contraception, safe sex, abuse, and some aspects of the law (such as consent).

4.0 Pregnancy risk and pregnancy experiences

4.1 Introduction

Women with intellectual disabilities are frequently considered unfit to parent or likely to produce children with disabilities (McCarthy, 1999). Historically, women with intellectual disability were institutionalised, routinely segregated, not given contraception choices, and sterilised, all with the aim of preventing child bearing (Waxman, 1994). Atkinson and Walmsley emphasised that while the policy in the past had been the protection of people with learning difficulties, the practice in relation to women was to prevent sexual relationships that might result in the birth of unwanted and possibly defective children (1995). Mayes, Llewellyn and McConnell (2006) argue that the legacy of these negative attitudes is that women with intellectual disability have been afforded less control over their bodies than their non-disabled peers; their reproductive capacity is commonly construed as a burden requiring suppression or elimination, rather than a normal part of womanhood.

There is a lack of empirical data on which to base practice in relation to the experience of pregnancy and childbirth for women with intellectual disability (McCray, 2000; Mayes et al., 2006). Knowledge is lacking generally about how women with intellectual disabilities feel about their fertility, about having or not having babies and raising or not having the opportunity to raise children (McCarthy, 2002). According to Mayes et al. (2006) the little research that does exist focuses on other people's reactions to the pregnancy. Such studies indicate that the reactions of people close to these women when they announce their pregnancies are almost exclusively negative (Booth and Booth, 1994, 1995; Llewellyn & Brigden, 1995). Few researchers - either in the disability field or researchers writing from a gender perspective - have studied the implications of pregnancy for women with disabilities (Mayes et al., 2006).

Notwithstanding the negative attitudes towards women with intellectual disability becoming pregnant, studies have revealed that adolescents with mild learning disabilities hold similar expectations to others of their own age concerning relationships and starting a family. Teachers' reports of secondary school students with mild learning disabilities revealed that the majority of students had ambitions for social intimacy, sexual

relationships, marriage, and having and raising children (Brantlinger, 1988, cited in McGaw & Sturmey, 1993).

McConnell, Mayes and Llewellyn (2008) contend that the number of women with intellectual disability now having children is thought to be increasing, citing evidence from Anderson, Byun, Larson and Lakin (2005) and Tarleton, Ward and Howarth (2006) (see also Pixa-Kettner, 2008). In England, the most recent figures come from the first national survey of adults with learning difficulties, which found that one in 15 of the 2,898 adults interviewed had children (Emerson, Malam, Davies and Spencer, 2005). McCabe and Cummins (1996) found a rate of 61 per cent in a small sample of Australian women living in the community (n=30). Meanwhile, Servais (2006) contends that pregnancy in general - whether planned or unplanned - is seemingly uncommon in women with intellectual disability, although he acknowledges that data on this is scarce. Servais (2006) argues that several factors make it difficult to assess pregnancy rates in this population; these factors include cultural differences in reproductive rights of individuals with intellectual disability, classification of pregnancy (for example, is pregnancy counted if terminated) and living environment (Servais, 2006). Studies of mothers with learning disabilities have shown that as few as 25 per cent of pregnancies are planned (McGaw, 1997). [80]

Much of the literature on this topic focuses on the prevention of pregnancy and contraceptive management (Conod & Servais, 2008; Elkins et al., 1986; Grimes, 1997). Meanwhile, there is a growing body of literature, particularly from Australia and the UK, which focuses on the parenting experiences of women with intellectual disability and supports necessary to assist them in this role. This literature will be discussed in Section 5.0 on Parenting.

Research from the early 1990s to the present has focused on the socio-cultural-historical and environmental factors influencing women with intellectual disability's experiences as mothers and the significant challenges they face. It has been argued that this is not surprising, given

80 Unfortunately, McGaw (1997) does not cite references for this statement in her article.

the significant opposition women with intellectual disability encounter when they become pregnant (McConnell et al., 2008; Mayes et al., 2006; Aunos & Feldman, 2002; Booth and Booth, 1994).

Risk factors for and the impact of an unplanned pregnancy on women with intellectual disability remain under-researched topics. What little there is in the literature will be discussed in this section.

4.2 Risk factors for unplanned pregnancy

4.2.1 Lack of knowledge surrounding sexual relations

Research carried out in Northern Ireland with 62 individuals with learning disabilities (39 individuals were aged between 13 and 25; 23 individuals were aged between 26 and 40) sought to gather their knowledge, personal experience and values and attitudes on a number of matters relating to sexuality and relationships including menstruation, masturbation, intimacy, sex and the law, reproduction, and sexual health (Simpson et al., 2006). [81] In relation to reproduction, interviewees were shown line drawings of pregnant women and asked to respond to related questions. In terms of their knowledge about sexuality and relationships:

- 71 per cent knew that a woman needed to have sex with a man to get pregnant.
- 68 per cent knew that a woman can get pregnant when she has sex for the first time.
- 52 per cent understood the meaning of the word adoption.
- 50 per cent understood the meaning of the word miscarriage.

81 The schools attended by the interviewees were used as an indicator of their level of disability: 29 attended a school for people with severe learning disabilities; 18 attended a mainstream school with facilities for people with learning disabilities; 10 attended a school for those with moderate learning disabilities and 1 attended a school for those with behavioural problems. The four remaining participants could not remember the name of their last school.

- 44 per cent knew that a pregnancy lasts for an average of nine months.
- Of the 56 interviewees asked about abortion, 36 per cent understood the meaning of the word. [82]

Dotson et al. (2003) carried out a small study gathering the perspectives of eight women with developmental disabilities in California, in the United States. The researchers conducted health and sexuality interviews with the women participants, a review of case records and interviews with the women's support staff. Their research revealed that while five of the women reported that they had had sex or were currently sexually active, half of the participants were unsure about whether or not they could become pregnant. Seven women reported that they had been pregnant in the past, and one woman was unsure whether she had been or not. Similarly, Murphy and O'Callaghan's research findings in England (2004) demonstrated that levels of sexual knowledge for adults with intellectual disabilities (mild to moderate) were far lower than for non-disabled 16 to 17 year olds. Findings demonstrated that levels of sexual knowledge for adults with intellectual disabilities (mild to moderate) were far lower than for non-disabled 16 to 17 year olds. Adults with intellectual disability in their study often lacked knowledge in a number of key areas, including pregnancy (one-third of the adults did not know how pregnancy occurred), contraception, and birth control.

4.2.2 Increased vulnerability and sexual abuse

Women with intellectual disability are vulnerable to sexual abuse due to their inability to defend themselves or to a lack of knowledge with respect to what constitutes abuse (Walsh et al., 2000). Furthermore, due to communication difficulties many women with intellectual disability may not be able to report symptoms of abuse, or an outcome of abuse, i.e. unwanted pregnancy. They are therefore reliant on others, including healthcare professionals, family members and carers, to be alert to symptoms of abuse and possible pregnancy such as trauma, or laceration of the hymen (Furman, 1989) as well as emotional symptoms

82 One school requested that the question on abortion was omitted from the interview.

such as anxiety, restlessness, fearfulness, apathy and withdrawal (McCarron & Kathryn Pekala Service, 2002).

Wingfield et al. (1994) contend that many women with intellectual disability are passive, obedient and affectionate, and thus at risk of sexual abuse; others may have multiple partners and are consequently at risk of unwanted pregnancies and sexually transmitted diseases (1994: 537). In this regard, Elkin et al. (1986) suggest that contraception alone does not address these issues, [83] and that sexuality counselling programmes for intellectually disabled women and their caregivers by specially trained personnel enable women to be educated about their sexual identity, acceptable social behaviour and avoidance of situations that could lead to sexual abuse or pregnancy.

Wheatley (2005) considers that young people with learning disabilities are sometimes vulnerable to peer pressure in a way their peers are not. She contends that many young people with mild to moderate learning difficulties are at risk of becoming involved in sexual activity when they are not ready. This can happen when young people start to experiment with being more independent and wanting to try new things such as smoking, going to places that they know might be dangerous, taking drugs (which could affect medication) or by experimenting with sex.

With regard to teenage pregnancy, psychological/demographic risk factors associated with girls becoming pregnant include low educational attainment, low self-esteem, poverty and low socioeconomic status (O'Keeffe, 2004). McCarthy (2002: 90) considers that many girls with intellectual disabilities would also fall into these risk categories, but she notes that there are no national or international statistics on pregnancies in girls and young women with intellectual disabilities.

Servais (2002) observed from his research that the fact that women with severe intellectual disability have or have had a boyfriend and that they live in a facility attended by people with milder intellectual disability may

83 It can be argued that this statement reflects historical attitudes towards women with intellectual disability and prevention of pregnancy.

be perceived as a risk factor for unwanted pregnancy, causing greater use of surgical methods to prevent pregnancy.

4.2.3 Self-esteem

Women with intellectual disability face challenges with issues of self-esteem, self-concept and body image, for instance as the result of the physical characteristics of syndromes (McCarron & Kathryn Pekala Service, 2002). In order to provide appropriate education and counselling for the woman and her support network, nurses and other healthcare providers need to have knowledge about the health needs and factors that affect coping (Kagan-Krieger, 2001).

4.2.4 Offsetting negative attitudes

Dixon (1996) notes that because of negative attitudes to women with intellectual disability becoming pregnant and taking on the role of mother, it is important that women with intellectual disability feel valued and that their self-esteem is maintained throughout their interactions with services, so as to optimise their ability to embrace motherhood.

4.3 Sex education for people with intellectual disability

It is now generally accepted that appropriate education with regard to issues of sexuality, tailored to the individual's unique learning style, can be effectively utilised in the management of fertility and menstruation difficulties (Sulpizi, 1996; Prevatt, 1998). McCarthy (1999) asserts that the aim of sexuality policies and guidelines should always be to support people with learning disabilities in their sexual lives, and not to dissuade them from having sex. The only justification, she contends, for dissuading people from having sex is if the risks they pose to themselves or others are very serious and cannot be lessened in any other way. McCarthy has emphasised the following points in relation to the provision of sex education for women with learning disabilities:

- Emphasis needs to be placed on self-esteem and assertiveness work for women with learning disabilities; this is not just in relation to sexual matters but also more generally in their lives. (This point stems from research she conducted demonstrating that 49 per cent of women (n=65) had had sex with a man or men without really wanting or enjoying it in its own right, i.e. they

were induced, coerced or felt it necessary in order to develop or maintain a relationship (McCarthy, 1996)).

- Sex education needs to emphasise a more active, less passive and accepting role for women with learning difficulties.

- Women with learning disabilities need to be supported in their sexual lives. The focus should be on empowerment, through helping women engage in a process of critical reflection about their sexual lives.

- It emerged from McCarthy's research (1999) that women did not receive sexual pleasure from much - and in some cases all - of their sexual activity with men (McCarthy, 1999). All sex education work with women with learning disabilities should therefore place a significant emphasis on women's sexual pleasure.

- Every learning-disability day and residential service should seek to ensure that at least some staff are ready, willing and able to discuss sexual matters with service users. This has implications for resources in terms of staff education and training, and staff time.

- More formal forms of sex education, such as one-to-one work or group sessions, should be carried out on a single-sex basis; this would offer a greater opportunity for the person with intellectual disability to identify with their advisor in these matters and to share life experiences (McCarthy, 1999).

- Cambridge and McCarthy (1997) considered that sexuality policies should ensure that proactive support is given to people with learning disabilities, meaning that issues related to sexuality, sexual abuse and sexual health should be routinely discussed as part of Individual Programme Plans (IPPs) or Individual Care Plans (ICPs) and reviewed at regular intervals.

4.3.1 Components of sex education programmes for people with intellectual disability

According to Whitehouse and McCabe (1997), although sex education curricula for people with intellectual disability exist (for example, Blanchett and Wolfe, 2002), more research is needed to establish the effectiveness of these programs beyond transmission of knowledge, to include global aspects of sexual health practices and abuse prevention. While there is conflicting evidence as to whether and how far sex education can protect people from abuse, McCarthy (1999) contends that it is still important that people with learning disabilities have access to it so that they can learn to differentiate between acceptable and unacceptable behaviour.

Steele & Cato (1989) note that providing appropriate sex education to women with intellectual disability may help them become more proficient at appropriate decision-making and help protect them from sexual abuse. Dotson et al. (2003) suggest that sex education inputs could include the following topics: friendship, intimacy, masturbation, non-conventional and safe sex practices, co-habitation, sexual side-effects of medication, sexual exploitation, social and protective skills and assertiveness training. Meanwhile, McGaw (1997) asserts that there is a pressing need to ensure that women with learning disabilities are given information about family roles, parenting responsibilities and child development in clear, simple terms. This should preferably happen during adolescence.

In relation to information about sexuality and relationships, Family Planning, New South Wales recommended that:

- Information needs to be provided over the long term, at a simple level, and with one-to-one follow up. People need opportunities to practise what they learn so they can generalise their skills. Concepts and skills need to be incorporated into the person's everyday life in their usual environments.

- For people to have control over their lives they require access to accurate information at the time when it is needed and presented in a way that is meaningful to them.

- Those who are working directly with people with a disability (teachers, service managers, nurses, group home staff and day programme staff) should provide such information (Chivers, 2006).

McCarron & Kathryn Pekala Service (2002) have found peer support groups for women with intellectual disability beneficial, especially with regard to discussion and understanding of the power discrepancies that are felt by women in general, as discussed by Walsh et al. (Walsh, Heller, Schupf and van Schrojenstein Lantman-de Valk, 2000). McCarthy (1999) discusses peer sex education and believes that it has the potential to be a powerful tool for change. However, it also needs to be acknowledged that people with learning disabilities would need training, support and supervision if they were to become involved in the delivery of sex education.

4.4 Challenges facing women with intellectual disability relating to pregnancy and parenting

4.4.1 Accessing sexual health information

Tarleton et al. (2006) assert that the provision of appropriate accessible information is a key strategy in supporting adults with learning difficulties to understand and make choices about whether or not they want to become parents. Resources in the UK have been produced to assist women with learning difficulties in decision-making (for example, a publication by the organisation CHANGE, Planning a Baby (Affleck, undated). Professionals involved in Tarleton et al.'s study (2006) [84] were concerned that adults with learning difficulties should be supported to understand the information provided and the choices available, where possible by an advocate. Providing this support themselves was very time consuming for staff.

In one area in England, the implications of parenthood were explained to students while they were still at special school (English, 2000). Here, a parents' group ran a workshop each year at a local special school, which

84 Including community nurses, advocates, psychologists, workers in adult services, occupational therapists.

introduced students not only to the joys of parenthood, but also to the difficulties.

4.4.2 Accessing sexual health services

It has been recognised that many women with intellectual disability do not have access to the same opportunities for choice, continuity and control, which form the basis of good practice, yet these factors are crucially important for these women (Campion, 1996). In many societies, general attitudes towards women with intellectual disability may result in the denial or marginalising of sexual health concerns. Such attitudes limit access to health services related to gynaecological care. According to Sulpizi (1996) women with intellectual disability may be treated as children, as it may be incorrectly assumed that they may not understand what is being told to them. As a consequence, health professionals may direct their questions and explanations to the non-disabled person accompanying them. It has been suggested that there are few health professionals who are willing and trained to address sexual health issues for women with intellectual disability (Schrojenstein Lantman-de Valk, Schupf and Patja, 2002).

A study of gynaecological services for women with intellectual disability in the US involving 127 women with developmental disabilities reported that 40 per cent of the women surveyed had not received health education regarding gynaecological care (Kopac, Fritz and Holt, 1998). Barriers to accessing services in general included:

- Financial difficulties
- Fear of examinations
- Difficulties in accessing healthcare professionals to provide such services.

4.4.3 Inadequate information

James (2004), writing from her experience as part of a Community Learning Disabilities Team in England, contends that despite considerable developments in education and health input for women with learning disabilities in recent years, many women remain poorly informed about contraception and the significance of changes in their menstrual pattern. As a result, such women may find it hard to

take realistic and informed decisions about family planning, or may fail initially to recognise their pregnancy. Failing to recognise their pregnancy also emerged as an issue for some of the women with cognitive impairment in Burgen's research (2008) carried out in Australia (discussed below). McGaw & Sturmey (1993) observed that the quality of women's antenatal care is often jeopardised by their late presentation to services and poor attendance at services.

4.4.4 Attitudes to pregnancy and parenthood

Women with intellectual disability have commonly experienced negative attitudes with regard to their sexual selves, to their forming friendships and romantic relationships and to their enjoying the same sexual freedom as their peers (Ferguson and Ferguson, 1996; Aunos and Feldman, 2002). Parents and other carers often have deep concerns about the emerging sexuality of girls and young women. These concerns focus on vulnerability to sexual abuse and fears of pregnancy (Heyman & Huckle, 1995). Llewellyn (1994) reported that announcement of pregnancy was often met with disbelief and dismay amongst family, friends, and the community more broadly. Such reactions can send a signal to a woman with intellectual disability about attitudes to her capacity to take on the role of mother and carer.

Booth and Booth (1995) similarly observed that becoming pregnant was seen as a mistake never to be repeated rather than an event to be celebrated. More recently, Mayes et al. (2006) also found that women labelled with intellectual disability encounter significant opposition to their child-bearing. This opposition may take the form of pressure to have an abortion (Booth and Booth, 1995) and the opposition may continue after child birth through not being allowed to take their baby home from hospital (IASSID Special Interest Research Group, 2008 [85]). In essence, Brown (1996) argues that negative attitudes about women with intellectual disabilities having children are still evident in the community and in professional practice, and these attitudes continue

85 The International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group (SIRG) on Parents and Parenting with Intellectual Disabilities includes scholars from a number of countries including the United States, Canada, England, Germany, The Netherlands, Sweden, Denmark, Iceland, Japan, Australia and New Zealand.

to have a significant impact on women's freedom to choose to take on gendered roles.

Areschoug (2005: 166), reviewing Swedish discourses related to birth control and adults with intellectual disabilities from 1967 – 2003, discusses a situation in the mid to late eighties and early nineties where women with intellectual disabilities withdrew from services (including, in one instance, an antenatal clinic) and were anxious to keep their pregnancy a secret for fear of control being taken from them or of being persuaded to have an abortion.

McConnell et al. (2008) examined whether poor mental health in mothers with intellectual disability was already evident during their pregnancy. The study involved 40 women with intellectual disability or self-reported learning difficulties, who participated in a series of pre- and post-partum interviews. A high level of anxiety was more common than either depression or stress in the sample. The authors propose that one possible explanation for this finding (in line with previous research) is the significant opposition to childbearing that these women face, and their fear that control over their pregnancy and their baby will be taken away from them by others (Booth & Booth, 1994; Llewellyn, 1994; Mayes et al., 2006). They recognised that further research was needed to determine whether the odds of pre-partum depression, anxiety and stress are greater in women with intellectual disability compared to the general population in Australia, and if so, to what extent. The findings nevertheless suggest that improved measures are needed to alleviate these negative emotional states during pregnancy, which are often compounded by the women's cognitive deficits (McConnell et al., 2008).

Mayes et al. (2006) investigated the lived experience of pregnancy through multiple interviews over time with 17 pregnant women with intellectual disability. To varying degrees, each woman negotiated her support networks to exclude people who were perceived as a threat and to include those who were supportive. The women's agency in doing so was a direct response to their anxiety about having control taken from them, and the fear of decisions being made by others about them and their unborn children.

4.5 Unplanned pregnancy among women with intellectual disability

4.5.1 Challenges in supporting women with intellectual disability experiencing unplanned pregnancy

There was a noticeable lack of research literature on unplanned pregnancy and women with intellectual disability. A number of authors referred to the challenges presented to health and social care staff in the provision of support to a woman with an unplanned pregnancy. For example, Klaar (1999), in her role as residential support worker for a woman with moderate learning disabilities in the UK, acknowledged that it was difficult to talk to the woman and her partner who had had an unplanned pregnancy about her possible options, i.e. parenthood, abortion, adoption, and about such issues as child protection. The woman in question received support from three sources: her key worker, her psychologist and a residential support worker. She also received support from family members.

Women with intellectual disabilities may also have difficulties in understanding the complexity of pregnancy, a challenge identified by some health and social care workers. Martin (2002), who works as a community nurse for people with learning disabilities in Tower Hamlets in London, contends that even where a woman has a mild or borderline learning disability, the complexity of pregnancy may prove beyond her comprehension. Martin (2002: 38) observed that pregnancy can seem very abstract to women, especially in its early stages when the baby is too small to be felt moving around or even show as a bump. In her experience, the general response from women on being asked what pregnancy meant to them was that they didn't know.

Martin (2002) notes that fear surrounding the birth can be as frightening for women with learning disabilities as for non-disabled women; however, this fear can be heightened by lack of knowledge and understanding. She found that the client group she worked with had particular anxiety about the birth, and that pain relief was of great concern to these women. She also observed that the women felt that they would have to cope alone during the birth. Martin (2002) also discussed the misconceptions that some women with intellectual disability had

about pregnancy and childbirth; for example, not knowing which part of her body the baby would come from.

As a response to this perceived lack of knowledge, Martin devised a pregnancy awareness form for use in GP surgeries by those performing pregnancy tests for women with learning disabilities. The form consists of a brief questionnaire that aims to provide the practitioner with information and give the woman an insight into the challenges she may have to face. Martin notes that the tool could also help improve communication and contact between generic and specialist community teams for people with learning disabilities (CTLD) services (in the UK context).

Burgen (2008) carried out research on women with cognitive impairment's experience of unplanned or unwanted pregnancy at the Royal Women's Hospital, Melbourne, Australia. The Royal Women's Hospital is the main provider of pregnancy options services and the researcher hypothesises that it would be the most likely destination for women with cognitive impairments to seek and avail of such services if experiencing an unplanned or unwanted pregnancy. The study examined data collected by the Pregnancy Advisory Service (PAS) for the years 2005 – 2007. Demographics and outcomes for women identified with cognitive impairment who contacted PAS for assistance were collated. A number of themes emerged from the data indicating that there were differences in the experiences of women with cognitive impairment compared to women in the general population, such as lack of knowledge about pregnancy and greater difficulty accessing the service. Emerging findings included:

- There was a low number of women with cognitive impairment identified who were in contact with the PAS over the data collection period (n=20)

- Most women relied on someone else to contact the PAS for them

- Late recognition of pregnancy featured:

- Nine women contacted the PAS at 12 weeks' gestation or later, compared with 20 per cent of all women who accessed PAS in 2006.
- Five women were at 18 or more weeks' gestation when PAS was contacted, compared with less than two per cent of all women who accessed PAS in 2006; two of these five women had several children and did not recognise the pregnancy signs.
- Issues associated with late recognition of pregnancy included the pregnancy being recognised too late to consider options.

- Delayed decision-making about options and contact with the PAS was evident:
  - Four women delayed four weeks or more.
  - Factors relevant to delayed decision-making were that there was a reliance on others for assistance.
  - The impact of family/partner's wishes arose. Three women did not proceed with the option of abortion and lost family/partner support; four women attended PAS only through worker intervention/assistance.

- Contact occurred too late for some women to consider the option of abortion; 10 women (50 per cent) proceeded with abortion compared with 80 per cent of all women who accessed PAS in 2006.

- The implications of this research, as identified by Burgen (2008, are that:
  - Women with intellectual disability need greater support to access contraception and health services
  - More appropriate and ongoing education and information on sexual and reproductive health is needed – especially in recognising pregnancy
  - Women's wishes are not always supported by her family/partner; therefore formal services and support may be needed.

Eastgate (2008), writing in the Australian context, notes that people with intellectual disability are legally assumed to have the same rights as anyone else when making decisions about pregnancy and child rearing. However, she observed that a woman with intellectual disability can face a number of difficulties in this process. If she decides to continue with the pregnancy and raise a child, the main burden is likely to fall on her family, who may or may not be willing to provide or be able to offer the level of support needed. The family may find it very difficult to accept that their daughter is or has been sexually active and, according to Booth and Booth (1995), in countries where abortion is available, a woman may be pressurised by her family into having an abortion.

Eastgate stresses that it is important to ascertain what the woman with intellectual disability wants herself, whether she is realistic about motherhood, and whether support is available to help her raise her child (2008: 258). If a woman decides to continue with her pregnancy, Eastgate (2008) advises that a number of issues need to be considered:

- Intensive support is likely to be needed, particularly when both parents have intellectual disability.

- Depending on the cause of the parents' disabilities their children may be at increased risk of having intellectual disability (Quilliam, Dalrymple and Whitmore, 2001).

- Children of parents with intellectual disability may face discrimination, isolation and difficulty with school achievement, even if they themselves do not have intellectual disability. Despite this, such children are usually positive about their parents.

- Parents with intellectual disability are likely to face financial difficulty while raising children, since most hold low-paid, if any, employment (Booth and Booth, 2000).

- It is important that the woman has information about and access to contraception after she has the baby. The reality of birth and child rearing may encourage her to prevent further pregnancies, which would make it easier to support her and her child.

Mayes et al. (2006) assert that GPs, midwives and other health professionals routinely in contact with expectant mothers may need to be especially vigilant against projecting pejorative beliefs about the decisions women with intellectual disability make for and about their babies. They should also be aware of the presence and potentially negative consequences of such attitudes on the mother as she prepares for her baby's arrival (Mayes et al., 2006). In Mayes et al.'s study, these attitudes were apparent in the women's stories and the women were fully aware of them.

Mayes et al. (2006) note that the short-term nature of disability support services may be unhelpful for providing women with support to make significant decisions for and about their unborn babies. The women clearly indicated that these decisions were made within the context of long-standing relationships, built on trust. They considered that support services for pregnant women with intellectual disability may need to be tailored to allow the longer term involvement of support workers with expectant mothers with intellectual disability. Support workers should also be sensitive to, and respectful of, decisions made in the context of a woman's intimate relationships (Mayes et al., 2006).

4.6 Research on experiences of pregnancy among women with an intellectual disability

In Mayes et al.'s research (2006), the lived, embodied experiences of pregnancy were explored by conducting multiple in-depth, semi-structured interviews with 17 women with disabilities while they were pregnant, in order to understand the phenomenon of becoming a mother. The majority of these were recruited during their first antenatal clinic appointment at two large public hospitals in an Australian city, where information outlining the nature and purpose of the study was distributed to them. Consenting participants completed a brief questionnaire which established whether women:

- Had received exceptional help at school (such as assistance from a remedial education teacher) due to a special learning need; and/or
- Had attended a special school specifically designed for children with special learning needs; and/or
- Had received in the past or currently received a disability pension related to a cognitive limitation; and/or

- Considered themselves to have learning difficulties or to be a slow learner and/or
- Had others describe them as a slow learner.

Women who answered affirmatively to any question were invited to participate in interviews about their pregnancy experience. Given that the questionnaire identified women with special learning needs, which were not limited to intellectual disability, participants also completed the Kaufman Brief Intelligence Test (Kaufman and Kaufman, 1990), which indicated that each had an IQ score of less than 80. This was done in order to capture the experiences of women thought to be in the mild and moderate ranges for intellectual disability, as well as women often considered to have 'borderline' intellectual disability or mild cognitive limitations (Tymchuk, Lakin and Luckasson, 2001).

The women ranged in age from 18-37 years; five were having their first child; five their second; two their third child; four women were having their fourth child, and one woman was having her fifth child. Thirteen women were in long-term relationships and four either were not in a relationship or their relationship had ended when the pregnancy was discovered.

The key themes emerging from this phenomenological study were:

- The women's stories illustrated that they experienced their pregnant bodies in much the same way as other women represented in the general literature on women's experiences of pregnancy and becoming a mother. For example, they were very pleased to feel their bodies adapting to accommodate the growing foetus, as they began to understand themselves as mother of the child they carried. Such descriptions of the experiences of women with intellectual disability challenge assumptions that women with intellectual disability do not experience, or desire to experience, the same things as other women (Brown, 1996). Mayes et al. (2006) stress that it is therefore inaccurate to consider them as degendered beings (Traustadottir, 1997).

- Women with intellectual disability have been constructed as passive, dependent, incapable and in need of support (Brown, 1996). Mayes et al.'s research demonstrated women's agency

in that they actively made decisions regarding whether the pregnancy would continue or not, how the baby would be cared for, and who would provide care.

- The women encountered significant opposition to their childbearing and to the decisions they made about their unborn babies. Fear of family intervention was a feature of the women's experiences; for example, one woman did not wish to disclose her pregnancy for fear of a negative reaction or action on the part of family members as well as fear that her child may eventually be taken from her; another woman was pressurised by her mother to have an abortion; another woman who was repeatedly raped decided to have her baby adopted, as the pregnancy was too advanced to have an abortion; another woman spoke of her shock at discovering her pregnancy, which was at an advanced stage, so she was unable to have an abortion.

- The women's decisions were not made in isolation from those closest to them, such as a partner and family members, those who supported their authority as a mother of the baby they carried, and those whose lives would be affected by the birth of the baby. Each woman identified at least one person who supported her decision-making regarding the child she carried.

- Mothering has been understood as a deeply embedded social occupation by researchers (Llewellyn and McConnell, 2004: 188), who have observed that carrying out the mothering role is influenced by those who can provide support for the mother (Booth and Booth, 2000; Llewellyn and McConnell, 2004). In Mayes et al.'s research (2006) the women's stories indicated an appreciation of the social nature of mothering work; they expected that they would need support and sought people around them to provide that support.

- The importance of women's social networks and significant support relationships leading up to the birth of a baby was highlighted: women with intellectual disability sought support in decision-making for a baby, prior to its birth.

4.7 Pregnancy outcomes in women with intellectual disability

McConnell et al. (2008a: 530) contend, based on their previous findings (McConnell, Mayes, Russo and Honey, 2003; Llewellyn & McConnell, 2002; Llewellyn, McConnell, Honey, Mayes and Russo, 2003), that pregnant women with intellectual disability typically have multiple risk profiles for adverse pregnancy and poor birth outcomes, including low literacy, low income and poor health. In addition, they are likely to have difficulty accessing quality antenatal care, given the fact that social and healthcare providers are generally not properly equipped to cater for their learning needs (Beange, McElduff and Baker, 1995; McConnell, Llewellyn and Bye, 1997; Kapell, Nightingale, Rodriguez, Lee, Zigman and Schupf, 1998).

McConnell et al.'s research (2008a) explored the prevalence of poor pregnancy and birth outcomes in women with intellectual disability and/or self-reported learning difficulties in an antenatal population. The research involved utilising antenatal clinic records in a socio-economically disadvantaged area of Sydney, Australia. Over a five-month period, all pregnant women attending their first appointment at two public hospitals (and who met the criteria of English proficiency) were invited to participate. Identification of intellectual disability was based on a social systems definition (Mercer, 1973): intellectual disability was identified when a woman had previously been labelled with intellectual disability by social services, and received supports and services exclusively for people with intellectual disability. An experienced health practitioner asked each woman attending her first antenatal clinic visit:

1) Had she ever been in a class or school for students with learning difficulties?
2) Did she receive a pension or benefit for a disability?

If so, then she answered additional questions to confirm that her placement in a special class or school was related to general learning difficulties rather than a specific learning difficulty, such as dyslexia, and/or to confirm that the disability pension was received for intellectual rather than another disability. Two additional 'screening' questions were asked to identify women who experienced difficulties with learning, but did not receive services or benefits for women labelled with intellectual disability. These were:

3) Did she think she had learning difficulties?
4) Did she think she was a slow learner?

The medical records for all participants were reviewed post-partum, with the consent of the women. The following variables were used in the analysis: indigenous status, previous pregnancies, antenatal care, medical conditions (including hypertension and diabetes), and birth outcomes (including birth weight, gestational age, Apgar scores and admission to neonatal intensive care (NICU) and/or special care nursery (SCN)).

The study identified a total of 57 pregnant women with intellectual disability and/or self-reported learning difficulties (total study cohort=878 pregnant women); the medical records of 54 of these women were accessible. Findings showed that these women experienced a higher rate of pre-eclampsia, had children with low birth weight more often and had children who were more frequently admitted to neonatal intensive care or special care nursery, compared with the women without ID or self-reported learning difficulties in the study cohort. The authors concluded that further research was necessary to determine the effects of biomedical risk factors (e.g. nutritional intake, maternal weight, smoking, and use of anti-epileptic and other medications); psychosocial risk factors, such as social support, stress, anxiety and depression; and, health system/service factors, including, for example, access to quality antenatal care.

The authors acknowledged that a major limitation of their research was that a comprehensive assessment of intellectual disability could not be undertaken in the busy antenatal clinic environment and therefore they could not determine severity of intellectual disability or whether there was any significant difference in general cognitive ability between the women with identified intellectual disability and those with self-reported learning difficulties. Further, they acknowledged that the readiness of women to self-report learning difficulties may be influenced by factors, such as low self-esteem, and/or mental health problems.

The authors suggested that one possible explanation for the higher admission rates to neonatal intensive care or special care nursery for babies of mothers with intellectual disability and/or self-reported learning difficulties could be that staff perceptions of maternal ability play a role in decisions about appropriate healthcare delivery.

4.8 Provision of services

4.8.1 Antenatal care services

All pregnant women - irrespective of their disability status - are entitled to receive the same range of free or affordable health care as provided to other persons, including in the area of reproductive health and antenatal care (UN Convention on the Rights of Persons with Disabilities, 2006). The literature acknowledges that there continue to be inadequacies in relation to access to equitable healthcare for women with intellectual disability, including pre- and post-natal care for mothers and their infants (Llewellyn et al., 2008). Such disadvantage is frequently accompanied by stigma and discrimination. According to a number of authors, women with intellectual disability are likely to have difficulty accessing quality antenatal care, given that health and social service providers are generally ill-equipped to accommodate their special learning needs (Beange et al., 1995; McConnell et al., 1997; Kapell et al., 1998). In addition, staff perceptions of maternal ability play a role in decisions made about appropriate healthcare delivery (McConnell et al., 2008).

A positive finding from McConnell et al.'s investigation (2008a) is that their study group participated in their first antenatal visit at around the same time in pregnancy as their non-disabled peers and continued their visits throughout their pregnancy (2008a: 534). However, Burgen's research (2008) demonstrated the opposite: there was delayed decision-making and contact with services amongst her sample. Meanwhile, a number of research studies involving women with intellectual disability have demonstrated late recognition of pregnancy and a consequent delayed decision-making around the pregnancy (Burgen, 2008; Mayes et al., 2006). According to Alison Giraud-Saunders, Co-Director of the Foundation for People with Learning Disabilities in the UK, there are problems in many areas when it comes to supporting parents with

learning disabilities. [86] In particular, they are often not known to learning disability services in pregnancy, even though it is vital that they have support and advocacy before childbirth. Research shows that the earlier services can get involved, the better the outcomes for the family (Tarleton et al., 2006).

Alison Giraud-Saunders also emphasises that children and family services are often unaware of a range of supports (including person-centred planning) that can be used and they often intervene in a crisis that could have been avoided, had the right support and advocacy been in place.

When women with learning disabilities do attend for antenatal care, they may have difficulty understanding the information and advice they receive or putting it into practice (James, 2004). Parents labelled with intellectual disability have great difficulty in accessing, understanding and applying popular literature and materials on pregnancy and parenthood. Standard healthcare literature, which adds to a gradual accumulation of knowledge and familiarity with pregnancy and child care issues for the general population, may be totally inaccessible to a woman with intellectual disability, so that pregnancy and childbirth can result in the additional stress of a very steep learning curve (Campion, 1996). Consequently, women with intellectual disability need specialist support to access antenatal services appropriately, so that their own health and that of the baby is not compromised (McGaw, 2000). The difference that specialised support can make in terms of physical and psychological benefits to mothers and babies has been described, for example, by Martin (2002). Parish and Markwick (1998) identified the need for an escort/advocate who understands the service being received by the woman with a learning disability. Women with a learning disability may also need explanation during the consultation with the GP or nurse, as well as discussion after examination in order that they may fully understand what has occurred.

86 Press release, Alison Giraud-Saunders, Co-Director of the Foundation for People with Learning Disabilities, accessed at http://www.learningdisabilities.org.uk/media/news-releases/news-releases-2006/09-may-2006a/

Research indicates that learning disabled mothers are poor attenders of services and vulnerable to hospital admission resulting from medical complications (McGaw, 1997). Therefore, preparing the mother for the birth and encouraging her to attend ante-natal classes is vital. Good practice occurs when GPs, community midwives and health visitors work closely alongside parents (as part of a core team of professionals across learning disabilities and children's specialisms), especially during the early stages of pregnancy. Campion (1996) issues a note of caution regarding professional services in that there can be a multitude of professionals involved with a pregnant woman with intellectual disability, such as child protection specialists, midwives, community nurses, GPs, psychiatrists, and clinical psychologists, who may give conflicting advice and create different expectations (Campion, 1996).

4.8.2 Tailoring services to intellectual disability

According to Tarleton et al., (2006), writing in the UK, many women with learning difficulties have not previously been in contact with services. According to Green and Vetere (2002) this means that many professionals in generic services who do come into contact with them have little knowledge or understanding about their support needs as people with learning difficulties. A number of tools for identifying parents with learning disabilities have been developed to help staff identify whether or not a person has a learning difficulty (Tarleton et al., 2006). [87]

Similarly, Campion suggests that once women become involved with maternity services, the issue arises of whether or not her learning disability will be identified. When a service identifies that a client has a learning disability it can either be sensitively incorporated into the tailoring of individualised support for the woman or it can be used as a label which creates concern in the professionals, depending on the approach of the service in question (Campion, 1996).

According to Baum & Burns (2007: 12) it is essential to raise awareness of parents with learning disabilities' support and communication needs with generic services such as ante-natal providers and midwifery, health visiting, and child social work services. Writing in the UK context, the

87 Tools for identifying parents with learning disabilities are discussed in Section 5.3.

authors add that professionals from specialist adult learning disabilities' teams are best placed to do this, by acting as a source of expertise for these services. This could include, for example, working alongside mainstream services in co-facilitating groups such as ante-natal classes or by promotion of accessible information in order that parents feel fully included in any interaction with services.

4.8.3 Adapting supports for pregnant women with intellectual disability

Adaptive methods and communication aids are needed to effectively support people with intellectual disability (Rodgers, 1994; Beange et al., 1995; Cooper, Melville and Morrison, 2004). Broughton and Thompson (2000) note that the capacity of women with a learning disability to give informed consent is likely to be influenced by the use of an understandable format for providing information.

To support one woman's pregnancy experiences, support workers met with medical staff in order to improve communication between medical staff and the woman. Complicated language was avoided, and repetition, pictures and role play were found to be useful (Klaar, 1999). McConnell et al. (2008a) suggest that the practice of audio-taping consultations, and availability of clearly illustrated educational resources written in plain language, could potentially contribute to effective healthcare consultations. The authors recommend that such resources be made available in the ante-natal clinic and their efficacy examined in this context.

According to Quartermaine (1999) clear communication and information are both essential in supporting decision-making for women with intellectual disability. Some women with intellectual disability cannot understand long sentences, so it is important to break language down into understandable, and easily interpreted concepts; clients with severe learning disabilities may not be able to clearly or effectively communicate or may speak a sign language such as Makaton basic sign language, or use their own system of signs or language. In addition, having an understanding of non-verbal communication is helpful (Dixon, 1996).

Klaar (1999) notes that social and healthcare professionals can make assumptions about a person's understanding, which can lead to confusion. In one example provided from the literature, a GP referred to a 'normal' labour, when discussing the possibility of the woman with intellectual disability in question having to undergo a Caesarean Section. The woman and her partner latched onto the word 'normal' and thought that that meant easier. The GP had assumed that what a 'normal' labour involved was common knowledge (Klaar, 1999). This highlights the importance of clear communication and the benefit of a woman having support when attending appointments.

Dotson et al. (2003) observed that it is important not to address questions and give information solely to accompanying parents or caregivers but to instead speak directly to the patient (Dotson et al., 2003).

4.8.4 Early identification of needs

In the UK, good practice guidance on working with parents with learning disabilities (DH and DfES, 2007) recommends that identification of needs should start when pregnancy is confirmed and that procedures, criteria and pathways should be confirmed between maternity services and children's and adults' social care. The authors note that early assessments of support needed to look after a new baby will help to prevent avoidable difficulties arising.

Tarleton et al. (2006) also recommend that if adults with learning difficulties decide to become parents, then contact with maternity services should occur as early as possible. In this study in the UK, professionals supporting parents with learning difficulties suggested that pro-active one-to-one work with parents should begin in the sixteenth week of pregnancy, with the community nurse supporting parents to understand the information provided by the midwife and to develop the required baby-care and other skills.

Meanwhile, Rogers (1997) has stated that early referral to the necessary support services is crucial, particularly for women who have been sexually abused or for women who have a history of poor parenting, with no positive parenting role model in their lives.

In relation to services, the Department of Health and the Department of Education and Skills in the UK note that an important starting point is to recognise that:

- Pregnant women with learning disabilities are entitled to universal services.

- Universal services are required to make 'reasonable adjustments' to make their services accessible and suitable for people with learning disabilities (DH and DfES, 2007).

Tarleton et al.'s study (2006) demonstrated that parents with learning difficulties needed support to attend (often over-subscribed) generic antenatal classes, even though they may feel that they do not 'fit in' there, as emerged in their study. One of the research participants in this study suggested that parents with learning difficulties should attend antenatal classes throughout their pregnancy, rather than just at the later stages like other parents, as this would give them more time and opportunity to absorb all the information available. In the same study one learning difficulties service reported that they ran a specific antenatal class, in conjunction with local midwives, for expectant parents with learning difficulties. These classes were seen as particularly valuable for parents who were frightened that their children might be removed from them.

In Tarleton et al.'s study (2006) workers supporting parents with learning difficulties described how they had been raising awareness within generic services about the support needs of parents with learning difficulties prior to the birth of their child through:

- The involvement of midwives and maternity service staff in the development of protocols and pathways.

- The development of a local 'maternity alliance' (involving all relevant professionals).

- The provision of information about the support available to parents with learning difficulties.

- Training for midwives about the support needs of parents with learning difficulties.

Workers might also need to raise awareness about parents with learning difficulties with the supervisor of midwives at each hospital, the midwife responsible for child protection and the local supervising authority for midwives (Kirby, 2003).

The London Royal College of Midwives' position paper on supporting women with disabilities in maternity services draws attention to the fact that health providers have a responsibility to address explicitly the existence of discrimination and its implications for care (The Royal College of Midwives, 2000).

4.9 Key findings

Findings in relation to the pregnancy experiences of women with intellectual disability included:

Pregnancy and intellectual disability

- There is a real lack of empirical data on which to base practice in relation to the experience of pregnancy and childbirth for women with intellectual disability (McCray, 2000; Mayes et al., 2006). Knowledge is lacking generally about how women with intellectual disabilities feel about their fertility, about having or not having babies and raising or not having the opportunity to raise children (McCarthy, 2002).

- Research that does exist indicates that the reactions of people close to these women when they announce their pregnancies are almost exclusively negative.

- The number of women with intellectual disability now having children is thought to be increasing. A recent study in England demonstrated that almost 7 per cent of a sample of 2,898 adults with learning difficulties had children (Emerson et al., 2005).

- Much of the literature in this area focuses on the prevention of pregnancy and contraceptive management. Research from the early 1990s to the present has focused on the socio-cultural-historical and environmental factors influencing women

with intellectual disability's experiences as mothers and the significant challenges they face. Risk factors for and the impact of an unplanned pregnancy on women with intellectual disability remain under-researched topics.

- Research has demonstrated that young women with mild learning disabilities hold similar expectations to others of their own age concerning social intimacy, sexual relationships, marriage, and having and rearing children. In one study in Northern Ireland, the majority of participants (with mild, moderate and severe intellectual disability) understood basic information about sex and pregnancy and 36 per cent (n=56) understood the meaning of the word abortion (Simpson et al., 2006).

Risk factors for unplanned pregnancy and sex education

- Risk factors for unplanned pregnancy included lack of sex knowledge, increased vulnerability and sexual abuse, low self-esteem, and negative attitudes.

- It is generally accepted that appropriate education with regard to issues of sexuality, tailored to the individual's unique learning style, can be effectively utilised in the management of fertility and menstruation difficulties. It has been asserted that the aim of sexuality policies and guidelines should always be to support people with learning disabilities in their sexual lives, and not to dissuade them from having sex (McCarthy, 1999).

- When undertaking sex education work with women with learning disabilities an emphasis needs to be placed on: self-esteem and assertiveness training; developing a more active, less passive role for women; supporting women to engage in a process of critical reflection about their sexual lives, and the importance of women's sexual pleasure. More formal sessions of sex education work should be carried out on single-sex basis.

- Possible components of a sex education programme that were considered to be useful included: global aspects of sexual health practices and abuse prevention, social and protective skills and assertiveness training, the difference between a friend and a boyfriend/girlfriend, intimacy, public versus private situations, non-conventional and safe sex practices, co-habitation, sexual side effects of medication, family roles, parenting responsibilities and child development.

- It was suggested that sexuality and relationships education should be provided over the long term, at a simple level, and with a one-to-one follow up. Information should be timely, and presented in a meaningful way to people (Family Planning, New South Wales).

- Peer support groups for women with intellectual disability were found to be beneficial, especially with regard to discussion and understanding of the power discrepancies that are felt by women in general (Walsh et al., 2000).

Challenges relating to pregnancy and parenting

- Challenges faced by women with intellectual disability experiencing pregnancy and parenthood emerged as: accessing sexual health information, accessing sexual health services, inadequate information, and attitudes to pregnancy and parenthood.

- A number of challenges emerged that were faced by health and social care services in the provision of support to women with intellectual disability experiencing unplanned pregnancy. These included difficulties in talking to a woman with an unplanned pregnancy about her possible options and about issues such as child protection; difficulties experienced by women with intellectual disability in understanding the complexity of pregnancy and its implications; fear surrounding the birth heightened by lack of knowledge; feelings of isolation; misconceptions about the pregnancy and childbirth as well as

lack of information about pregnancy in general, and difficulties accessing services.

- It has been noted that in relation to pregnancy it is important to ascertain what the woman with intellectual disability wants herself, whether she is realistic about motherhood, and whether support is available to help her raise her child.

- Research carried out in Australia on 17 women's experiences of pregnancy demonstrated:
    - The women's stories illustrated that they experienced their pregnant bodies in much the same way as other women.
    - The women actively made decisions regarding continuing with the pregnancy or not.
    - The women encountered significant opposition to their childbearing and to the decisions they made about their unborn babies.
    - Their decisions were not made in isolation from those closest to them, such as partners and family members, those who supported their authority as a mother, and those whose lives would be affected by the birth of the baby.
    - The women's stories indicated an appreciation of the social nature of mothering work; they expected that they would need support and sought people around them to provide that support.
    - The importance of women's social networks or significant support relationships leading up to the birth of a baby was highlighted.

- Other research in Australia (McConnell et al., 2008) explored the prevalence of poor pregnancy and birth outcomes in women with intellectual disability and/or self-reported learning difficulties in an antenatal population. The findings showed that these women (n=54) experienced a higher rate of pre-eclampsia, had children with low birth weight more often and were more frequently admitted to neonatal intensive care or special care nursery compared to the non-disabled cohort in the study.

Accessing services

- The literature acknowledges that there continue to be inadequacies in relation to access to equitable healthcare for women with intellectual disability, including pre- and post-natal care for mothers and their infants. Women with intellectual disability are likely to have difficulty accessing quality antenatal care, given that health and social service providers are generally ill-equipped to accommodate their special learning needs. Staff perceptions of maternal ability play a role in decisions made about appropriate healthcare delivery (McConnell et al., 2008).

- Research findings in relation to how women with intellectual disability interact with services included: low numbers of women making contact with pregnancy advisory services (Burgen, 2008); reliance on others to make contact with services (Burgen, 2008); late recognition of pregnancy (Burgen, 2008; Mayes et al., 2006); delayed decision-making and consideration of options (Burgen, 2008; Mayes et al., 2006); difficulties in understanding the information received and putting it into practice (James, 2004); information deficit based on having not been able to access popular literature on pregnancy and parenthood (James, 2004) Other problems highlighted by a UK-based disability organisation in providing support to women with intellectual disability were that women were often not known to learning disability services during pregnancy and that there was a lack of integration across services.

Tailoring services to intellectual disability

- The use of repetition, pictures and role play, the practice of audio-taping consultations, and the availability of clearly illustrated educational resources written in plain language have been recommended as a way of contributing to effective healthcare consultations (Klaar, 1999, McConnell, 2008).

- Good practice guidance on working with parents with learning disabilities has recommended that identification of needs should start when pregnancy is confirmed and that procedures, criteria

and pathways should be confirmed between maternity services and social care services (DH and DfES, 2007).

- In relation to services, it has been recognised that an important starting point is to recognise that pregnant women with learning disabilities are entitled not to be discriminated against in relation to services. Moreover, services are required to make reasonable adjustments to make their services accessible and suitable for people with learning disabilities (subject to legal provisions and exemptions).

5.0 Parenting

5.1 Introduction

Being a parent is an important marker of adulthood and maturity. Women with intellectual disabilities have been viewed as childlike, implying that they are not capable of taking on adult roles. Stereotypical views of women with intellectual disabilities make it difficult for groups in society to imagine they could be parents. This has led to many challenges for people with intellectual disability who become or want to become parents (Llewellyn and McConnell, 2005).

According to Booth et al. (2005), writing from the UK perspective, several factors make it difficult to estimate the number of parents labelled with intellectual disability. These include the lack of a common definition of intellectual disability, variable population screening and diagnostic practices, inconsistent record-keeping, and the invisibility of many parents to official agencies. Consequently, mothers and fathers labelled with intellectual disability constitute a hidden population, whose size is hard to estimate. In the UK estimates vary widely, from 23,000 to 250,000 (DH and DfES, 2007). An English study (Emerson et al. 2005) found that almost 7% of adults with 'learning difficulties' were parents. Pixa-Kettner (2008) conducted a survey on parents with intellectual disability in Germany. Questionnaires requesting information about all children born to adults with intellectual disability since 1990 were sent to service providers (n=701) in the summer of 2005. The study confirmed the trend from an earlier study carried out in 199, of a continually increasing number of parents with intellectual disability. A total of 1584 cases of parenthood were reported for the period 1990 – 2005. The proportion of children living with at least one biological parent with an intellectual disability had increased from 40% to 57% between 1998 and 2005. At the time of the review, comprehensive data on the total number of parents with learning disabilities in Ireland was not available.

Despite difficulties in estimating correct numbers for this population, across a number of countries including the UK, Australia, and Germany there are increasing numbers of parents with learning disabilities in contact with services (DH and DfES, 2007; Bradley, Toft and Collins, 2000; Guinea, 2001). Pixa-Kettner makes the point that the increasing number

of parents with intellectual disabilities in Germany is an indication that this group are living a more 'normal' life. Their results indicated a trend towards increased independence and greater recognition of the importance of biological parents (Pixa-Kettner, 2008: 318).

According to Atkinson and Walmsley (1995) motherhood for women with learning difficulties still tends to be discouraged, and when it happens, it is strictly regulated. There are external factors that impinge on women's experiences of motherhood, and also learnt prohibitions, which women have internalised. Atkinson and Walmsley contend that women with learning difficulties face particular pressures to conform to traditional gender roles in which they undertake domestic and caring work in the private sphere of the home (1995: 227). Therefore, even though sexual relationships and marriage are more likely for women with learning difficulties than they were previously, the division of labour in the home itself may reflect traditional sex roles and, in practice, motherhood often remains an unachievable goal (Williams, 1992).

Llewellyn and McConnell (2005) report on the key lessons from the narratives of five families. Their stories highlight the heterogeneity of parents with intellectual disability, in their personalities, life experiences, living situations, the people in their lives and the ways in which they learn and adapt to parenthood. The second lesson is that as a group, they face predictable challenges, related to the intellectual disability label. Parents with intellectual disabilities face low expectations about their abilities, capacity and potential to take on parenting. Furthermore, many parents with intellectual disabilities live in difficult socioeconomic and personal circumstances, including being in receipt of social welfare, living in poorer areas and having little opportunity to access appropriate or useful support to rear their children. Thirdly, the stories demonstrated their shared achievements and resilience in the face of hardship, as well as their efforts to demonstrate their ability to do things 'normally'. Booth and Booth (1994) suggest that one of the rewards of parenthood for people with learning disabilities is the adult status it brings, increasing the sense of identification with other parents, and thus positive perceptions and self-esteem, personal fulfilment, opportunities for integration and loving relationships.

5.2 Approaches to understanding issues for parents with intellectual disability

Llewellyn et al. (2008: 293) identify three phases of research on parenting and adults with learning disabilities over the past six decades. The first phase, from the 1940s, primarily concentrated on the heritability of intellectual disability. Nowadays, researchers no longer ask questions about whether people with intellectual disability should or should not be allowed to have children. Nevertheless, community and social attitudes can still be at variance with research evidence. During the second phase, researchers turned their attention to parenting adequacy and parenting training. The third and current phase centres on a greater concern for the family, community and social context in which parents with intellectual disability and their children are located rather than on the individual parent.

Reinders' analysis (2008) demonstrates how the principle of equality has guided research in the Netherlands and its importance in highlighting discriminatory responses based on stereotypes of people with intellectual disability as parents. He concludes (from an analysis of the debates surrounding parenting by people with intellectual disabilities) that there is not one cause for the difficulties experienced by some parents with intellectual disability, and that designating psychological factors as the differential cause is inadequate.

5.3 Tools for identifying parents with intellectual disabilities

According to Tarleton et al. (2006), a number of tools for identifying parents with learning disabilities have been developed in the UK to help staff identify whether a person has a learning difficulty. The Sanderson Screening Tool (also referred to as the STRAP-LD (Screening Tool Relating to the Assessment of Parents with suspected Learning Difficulties)) was designed to enable non-psychologists to carry out a brief assessment with parents with suspected learning difficulties, to indicate whether a referral to clinical psychology services is necessary. This test was developed for health visitors, midwives, social workers and other professionals and involves asking the adult to read a passage. Scores are provided for the number of mistakes made. The adult is then asked eight questions about the information in the passage. The tool is then returned to the psychology department that developed it, who

then advise whether the scores indicate learning disability (McDonnell & Hames, 2005).

5.4 Assessments of 'competence' among parents with intellectual disability

McConnell et al. (2008a) note that a consistent finding from the literature is that maternal IQ is not systematically correlated with parenting competence (Tymchuk & Feldman, 1991; Booth & Booth, 1993; Dowdney & Skuse, 1993). There is no point on a scale of intelligence below which a person becomes a bad parent, just as there is no point on a scale of intelligence above which a person becomes a good parent (Gates, 2007). Research does, however, suggest that people with learning disabilities may have difficulties in bringing up children, and may be at greater risk of becoming involved with child protection services (Feldman 1994; Sheerin, 1998).

Research has also demonstrated a concern with the outcomes for children of parents with intellectual disabilities, and attention has been directed to the quality of care provided by parents with intellectual disability. Llewellyn & McConnell's research in Australia demonstrated a substantial variation among children of parents with learning disabilities, with most children meeting age-norm expectations. A key factor was the presence of at least one consistent and supportive adult in a child's life (Llewellyn & McConnell, 2005). Despite this evidence, family and children's court studies in Australia, the USA and the UK suggest that parents with learning disabilities are 15 to 50 times more likely than other parents in the community to have their children removed and placed in care (Llewellyn & McConnell, 2005). The international literature indicates that up to 48 per cent of all children born to parents with intellectual disabilities will be removed, with figures of 33 per cent in Australia (Llewellyn, McConnell and Ferronato, 2003c; Booth, Booth and McConnell, 2004).

In a survey carried out in the Netherlands in 2004 with 1,500 families with either one or both parents having an intellectual disability, it was observed that 33 per cent of families functioned in a way that was considered to fall into the category of 'good enough' parenting (Willems, De Vries, Isarin and Reinders, 2007). 'Good enough' parenting involved

fulfilling three conditions: (i) there was no sign that children were abused or neglected, (ii) there was no interference from a child protection agency, (iii) there was no court ordered displacement of children in foster care. The main aim of the survey was to identify indicators explaining why parenting went well in these families. In relation to this aim, the following issues were identified in the qualitative part of the study:

- The condition and degree of the intellectual disability per se was not a strong indicator of success or failure.
- Inadequate professional support was a strong indicator of failure.
- The presence of a social network acting in support of the parents was a strong indicator of success.
- People's unwillingness to accept support and follow advice tended to result in difficult conditions of family life.

A consistent finding from the literature is that mothers with intellectual disability typically experience poverty and hardship in raising their children (McConnell et al., 2003b). Reinders' analysis (2008) points to the research literature, which has demonstrated that parents with intellectual disability are usually poor and with a lower health status than that of the general population (Emerson and Hatton, 2007). Moreover, such parents are usually socially isolated and consequently lack the supports necessary to escape psychological stress. McGaw (1997) has noted from her experience that social isolation and dysfunctional relationships are the most commonly reported problems cited by parents with learning disabilities. In particular, families reported difficulties with the development and maintenance of relationships, and disengaging from inter-family fighting (McGaw, 1997: 125). Many professionals recognised that family stresses could have been avoided, or their impact lessened, if only parents had been provided with some support and guidance at an earlier stage (McGaw, 1997).

5.5 Role of family networks in supporting parents with intellectual disability

Traustadottir and Sigurjonsdottir (2008) used qualitative methods to study three generations of Icelandic mothers with intellectual disabilities and their children over half a century (1950-2005). Eighteen mothers participated in the study. Data were collected through participant

observation, in-depth interviews with mothers, their children, partners, extended family members and professionals. The authors found that despite the development of formal support services, the importance of assistance from extended family continued to be crucial in determining whether mothers with intellectual disabilities retained custody of their children. In-depth examination of the support offered by family members revealed that women relatives referred to as 'mothers' played the most important role. The 'mother' was a non-disabled woman who provided practical and emotional assistance and advocated on behalf of the disabled mother and her family. If successful, the 'mother's' advocacy was found to play a crucial role in facilitating the maintenance of the custody of the children by their birth mothers.

The 'mothers' who were successful in their advocacy role were accepted by the professionals as partners in planning and providing services for the mother with intellectual disability. The professionals seemed to be more inclined to accept the 'mothers' as partners if they were the ones who initiated contact with social services and asked for assistance while the intellectually disabled mother was still pregnant. Professionals seemed to identify with the 'mother' and viewed her as a responsible individual who had similar views towards the 'case' as they had themselves.

It also seemed to help if the disabled mother was living with the father of the child when the 'mother' first contacted social services. This seemed to indicate 'respectability', which the system favoured: the expectant mother was regarded as sexually responsible, and the child was perceived as growing up within a stable traditional family pattern.

The authors concluded that the establishment of services did not diminish the importance of support from extended family networks. Rather, it has influenced the kind of assistance needed from family members, pointing to a more active advocacy role. This role involved negotiating with service professionals as well as protecting mothers from negative attitudes on the part of professionals and support workers within the health, social, and child protection services. The importance of the family support network continued to be crucial for the mothers with intellectual disability in keeping their children.

Tarleton et al.'s study looked at the role of extended families in providing support to parents with intellectual disability (2006). A national survey of adults with learning difficulties in England (Emerson et al., 2005) found that 58 per cent of the parents with learning difficulties, who still had their children living with them, were themselves living either with their own parents (15%) or other relatives (43%).

Some professionals in this study mentioned instances where interested families had not been informed when major decisions were made about children, including cases of abortion and adoption (Tarleton et al., 2006). Elsewhere, the involvement of extended families was often inhibited by the lack of family members living locally. Good practice was identified where the involvement of the wider family is supportive or 'protective' (Barlow, 1999) and where the parent can retain control. Research has indicated that in some cases, families can sometimes 'take over' or undermine professionals' relationship with parents with intellectual disability (Tarleton et al., 2006). Professionals reported trying to maintain a careful balance between keeping parents with intellectual disability's needs paramount, while also involving family members where appropriate and understanding the issues from their perspective.

Tarleton et al.'s research identified a number of strategies for involving extended families, including:

- Spending the time needed to develop the trust of extended families.
- Observing and listening carefully, to understand the particular roles of individual family members.
- Explaining to family members the support provided to parents and the child protection system, ensuring particularly that family members understand that within judicial proceedings normal confidentiality rules do not apply.
- Keeping families informed of developments (with the consent of the parents with intellectual disability) by having meetings with the parents and the family together, where appropriate.

- Clearly outlining professionals' and advocates' roles, and their boundaries.

- Remaining vigilant about the impact of the level of involvement of extended family members so that family relationships do not deteriorate.

- Not getting involved in family feuds.

5.6 Role of social networks in supporting parents with intellectual disability

In the Australian context, Llewellyn and McConnell (2002) investigated mothers' views about the types of support they get and from where they get that support. The study was based on interviews with 70 mothers with intellectual disability using a support interview guide designed to accommodate the mothers' cognitive difficulties. [88] Key findings highlighted by the authors were:

- Family members were central in the support networks of mothers with intellectual disability with pre-school age children. Mothers with cognitive difficulties felt closest to and most comfortable with family members, who provided more types of support (practical/tangible as well as emotional support) than formal ties or friends and neighbours.

- Service providers formed the second largest group of supportive ties and they were the mothers' primary source of information and advice; however, relationships with service providers were relatively short-term and characterised by relatively infrequent contact. Mothers with intellectual disability in general felt less comfortable in seeking support from them.
- Few mothers with intellectual disability could identify supportive ties with friends and neighbours, suggesting that they were isolated from their local communities and were potentially

88 The sample was comprised of mothers of pre-school age children (i.e. < 6 years) who participated in three studies over a four-year period. Participants in the study were those described by social service agencies as having learning disabilities.

vulnerable if a breakdown occurred in the support provided by their families.

- Mothers with intellectual disability living alone had service-centred networks; mothers living with a partner had family-centred networks and mothers living in a parent/parent-figure household had local, family centred networks.

The overall conclusion was that these mothers did not live in a social vacuum, but many were socially isolated. The implications of the findings included the need for service providers to be sensitive to the variations in mothers with intellectual disabilities' support networks. The study also found that particular attention needs to be paid to the varying involvement of different groups of people and the types of support that they offer in relation to mothers' living arrangements.

Of particular concern was the group of single mothers who lived alone and who had few long-term relationships that could offer emotional support; the challenge, therefore, is to devise ways in which these mothers can be assisted to develop local, community-based support networks to help in the demanding task of raising children.

It has been recognised that the task of parenting may be daunting for parents with intellectual disability and that relatively restricted social networks play a role in this (Murphy and Feldman, 2002). Feldman, Varghese, Ramsay and Rajska (2002) examined the relationships between parenting stress, social support and mother-child interactions in 30 mothers with intellectual disabilities residing in small cities (population less than 100,000), towns and rural areas of eastern Ontario, Canada. [89] Feldman et al. found that the stress levels of parents with intellectual disability were very high (compared to the general population) and their self-reported need for social support was also high. Parents with

89 A social system definition of intellectual disability (Mercer 1973) was used to determine eligibility for this study. Based on diagnostic assessments, school (and more recent) records, the provincial social services ministry deemed all study participants eligible for adult services and financial supports exclusively for persons with intellectual disabilities (synonymous with the term 'mental. retardation').

intellectual disability had relatively poor support networks but those who showed higher levels of satisfaction with their social support networks had both lower stress levels and more positive maternal behaviours in interactions with their children.

The findings highlighted the potentially crucial role of perceived competency-enhancing supports in promoting positive parenting practices in parents with intellectual disabilities. Feldman et al. (2002) observed that the parents' perception of supports was more important than the actual amount of support provided in shielding them from the negative effects of stress. The authors observed that having a large support network does not necessarily mean that the parent considers all these people and organizations helpful. They note that competency and self-esteem may be enhanced by some support approaches (such as empowerment and positive reinforcement for improvements) and inhibited by others (such as control and criticism) (Tucker & Johnson, 1989; Feldman 2002a). The authors also suggest that other factors besides the parents' disability status are likely to affect parenting abilities and these variables should be considered when assessing the parental competence of these parents (Feldman 1998, 2002a). Limitations of the study included inability to confirm the level of disability of mothers; the fact that the instruments used for measuring parental stress, social support and parent-child interactions had not been standardised for use with people with intellectual disability; and small sample size.

Stenfert Kroese, Hussein, Clifford and Ahmed (2002), in a similar study in the UK, interviewed a small group of mothers with intellectual disability to explore their psychological well-being and social networks. They confirmed the small size of people's networks, a reliance on family contacts (70 per cent of contacts were family members) and the fact that not all the social contacts (including partners) were experienced as helpful. The authors reported that there were strong positive relationships between mothers with intellectual disability's psychological well-being and the size and helpfulness of their social network.

These studies suggest that one way of improving the outcome for parents with intellectual disability would be to help them build positive social networks.

More recent research on mothers' social support networks involving a phenomenological study with 17 women in Australia, [90] demonstrated women's agency in the creation of support networks prior to a baby's birth, and secondly, practical assistance was sought only from people who affirmed the central role of the woman in the life of her baby (Mayes et al., 2008). The findings have implications for practice as follows:

- Disability and family-support practitioners should consider their position in a mother's support network; the experiences of the women in the study demonstrated that a mother's social context can either support her or undermine her as a mother. This, the authors suggest, is a sound reason to include the support of others in any parenting capacity assessment carried out on mothers with intellectual disability (Booth and Booth, 2002).

- Practitioners need to consider the amount of control a woman is able to exert over those involved with her family, being sensitive to the fact that the woman may view professional involvement as an attempt to decentre the support network she has negotiated for herself and her baby.

- The research indicated that new questions should be included in support provision for mothers, including - from the mother's perspective - who in the network believes in her ability as mother; who is / was supportive while she is / was pregnant; and who can she count on for assistance without fear that they will attempt to 'take over' the care of her child.

5.7 Professional and training supports for parents with intellectual disability

For women with intellectual disability who become mothers their childhood is generally marked by little opportunity to learn the skills needed to care for a dependent child (Llewellyn et al., 1997). A substantial body of work demonstrates that parents with intellectual disability can adequately care for their children given appropriate

90 Same sample as Mayes et al. (2006) described in Section 4.0 on pregnancy experiences above.

support and identifies the critical dimensions of effective support and training. For instance, Alexander Tymchuk in North America and Maurice Feldman in Canada used behavioural techniques to teach parenting tasks to parents with intellectual disabilities. These techniques include the opportunity to learn skills in the situation where these will be applied, the use of illustrated material and demonstration, and practice opportunities with positive reinforcement (Llewellyn & McConnell, 2005). A common concern (voiced by teachers and support services) is that people with learning disabilities will fail to anticipate the demands that their children will make on them (as is also common for the general population) and that they will treat their children like 'dolls'. In reality, according to McGaw (1997), this rarely happens.

Meanwhile, training programmes for parents with intellectual disability often deal with parental tasks typically concerning young children like bathing, nappy changing and language development (e.g. Feldman, Sparks and Case, 1993; Feldman & Case, 1999) while parental need for support beyond this is often neglected. McGaw (2004:232) stresses that parents with intellectual disability require lifelong services to assist them in meeting the challenges of their children as they become older. Research has indicated that professional help is directed predominantly towards parents with younger children, while the support requirements of parents of older children (in dealing with issues such as school enrolment, discontinuation of after school care and puberty problems) are not being met (Pixa-Kettner, 2008).

5.7.1 Parent training programmes

Parent training programmes are now recognised as only one component of essential support services for parents with an intellectual disability (Mirfin-Veitch, 2003). Booth and Booth (1996) are critical of what they perceive as a narrow focus on short-term training in specific skills and reactive responses to crisis. Such an approach, they argue, is based on a 'deficit model' of service delivery, which is resource led and crisis driven, focusing primarily on the person's failings, and putting all the control in the hands of the professional.

It has been clear for some time that parents with intellectual disability can learn new skills, including parenting skills, from group and individual parent training programmes (Feldman, 1994). Brown (1996) asserts that

while training programmes work to some extent, what is needed is long-term instrumental assistance with such issues as money management, meals and nutrition and accessing health and educational services (McGaw, 1996). A consistent finding from the literature is that mothers with intellectual disability learn parenting skills when training and support is appropriately tailored to their circumstances and learning needs (Feldman, 1994; Ray, Rubenstein and Russo, 1994; Llewellyn et al., 2003a). Meanwhile, McCray asserts that support by means of counselling and a more holistic approach is likely to be most appropriate (McCray, 2000).

Mirfin-Veitch (2003) lists the content areas that have been identified as areas of greatest need in relation to training. These training needs include basic childcare, health and safety (Dowdney and Skuse, 1993; Feldman et al., 1993); basic skills; problem-solving skills (Mirfin-Veitch, Bray, Williams, Clarkson and Belton, 1999); decision-making processes in real life (Tymchuk, Yokota and Rahbar, 1990); skills in developing friendships (Booth and Booth, 1993a); self-esteem and assertiveness skills (McConnell et al., 1997); managing money (Mirfin-Veitch et al., 1999); and behaviour management skills (Mirfin-Veitch et al., 1999).

Murphy and Feldman (2002) highlight the fact that generic parent training services have been offered on an out-of-home basis, which has led to difficulties for parents with intellectual disability in applying that knowledge to the home setting. Home-based programmes have been shown to be more effective than out-of-home programmes in teaching the parents the necessary skills in Sydney, where the researchers described their ten-session home-based programme for teaching parents the necessary skills in relation to dangers, accidents and childhood illnesses in young children under four years of age (Llewellyn, McConnell, Russo, Mayes and Honey, 2002a). An analysis of case study notes and parent feedback at the end of the project indicated that the parents preferred interactive and practical learning to verbal learning. They liked having pictorial aids, achievable, individualised plans for their home with regard to safety improvements, material matched to their child's needs and lessons that were not too long (60 minutes was considered too long by many parents).

While most parent education programmes focus on the teaching of parenting skills, McGaw, Ball and Clark (2002) set up a parent group with a different focus. Their parent group met for 14 sessions and concentrated on relationships issues (such as recognising and managing emotions, trusting others, using negotiating skills), employing a cognitive behavioural approach. They found that parents who took part in the group had a more positive self-concept and had improved relationships (with, for example, partners or friends) by the end compared to a group of parents who did not attend the sessions. The group itself acted as a way of extending parents' social networks, with some of the relationships formed in the group continuing after the group disbanded.

5.7.2 Competence-promoting support programmes

Tucker and Johnson (1989) distinguished between competence-promoting type support, which helped parents to learn and achieve by themselves, and competence-inhibiting support, which involved 'doing' for the parents rather than helping them to learn and achieve for themselves. Competence-inhibiting support denied parents the opportunity to learn, undermined their confidence and made their situation worse. A key factor in determining the effectiveness of support is how parents perceive the support they are offered (Llewellyn & McConnell, 2005).

Gates (2007: 561) identified four main areas of support:

1. Practical help and teaching
2. The attitudes of professionals and the services they represent: People with disabilities should be given their full and proper status as parents first (Booth and Booth, 1994a)
3. Need of all parents to make supportive relationships with friends in their local area. Research suggests that this need is particularly relevant to parents who have a learning disability (Campion, 1995; Booth and Booth, 2000)
4. Supports related to the environment: Parents with intellectual disability are more likely to experience, for example, poverty and poor housing; this disadvantage is often worsened by prejudice and stereotypical attitudes. It is essential that professionals understand the impact of these factors on a family.

5.8 Adequacy of training and support services

Booth and Booth (2003) note difficulties in recruiting and retaining mothers and fathers with learning difficulties in early intervention groups, parenting programmes, family centres, and antenatal classes in the UK. They argue that these difficulties are too easily blamed on the parents with learning difficulties themselves when they owe more to shortcomings in the delivery of these services. Booth and Booth (2003) have suggested some reasons for parents' reticence in taking part in support programmes, centring around experiences of disadvantage and exclusion. Reasons Booth and Booth identified for parents' reluctance to take part in support programmes included fear of having their children taken away, often leading them to regard professionals as a possible threat; difficulties experienced with reading, writing, telling the time and using public transport; being overburdened by day-to-day problems.

Pixa-Kettner (2008: 319) raised the question of whether a possible mistrust by parents with intellectual disability of professional support services was based on their fears that children might be removed from them if they had contact with support services. Many parents have spent their life trying to avoid the label of intellectual disability, and therefore steer clear of experiences that bring that stigma to mind (McGaw, 1996). Other common pressures impacting on the participation of parents with intellectual disability were clinical depression, child-care proceedings, jealous partners, poor health and unavoidable commitments. Despite these barriers, though, the successful Support and Learning Programme (a joint venture between the University of Sheffield and Sheffield Women's Cultural Club, which ran from 1999 to 2001 and involved personal support and development in self-advocacy to 31 mothers with learning difficulties) showed that mothers will accept support if it is provided in a manner that is tailored to their needs (Booth and Booth, 2003).

Research in the area of parental supports has tended to focus on providers' opinions (Newton, Horner, Ard, Lebaron and Sappington, 1994). Guinea (2001) draws attention to the need to gather the perspectives of people with learning disabilities themselves on the types of supports they would find beneficial. Her findings - involving semi-structured interviews

with eight parents with learning disabilities - supported the view from elsewhere (Lindsay, Michie, Baty, Smith and Miller, 1994) that people with learning disabilities can express views consistently. The parents in her study were able to distinguish between the support provided to them, and what they wished was provided.

5.9 Features of effective support for parents with intellectual disability

Booth and Booth (2003) identified examples of good practice in provision of parental support. They summarised good practice as occurring:

- Where there is a belief that with the right kind of support parents can succeed - as opposed to what Booth and Booth (1993) have identified as the commonly featured 'presumption of incompetence' (Booth & Booth, 1993) and the resulting 'expectation of failure' (Watkins, 1995) found among generic service providers.

- Where services recognise the importance of advocacy support for parents both as 'a defence against the risks of system abuse' (Booth and Booth, 2003) and as a factor that will improve their self-esteem. Nicholson (1997) found that advocacy support for parents was rated as important by professionals but was poor in terms of both quality and access.

- Where services have an understanding of the value and place of specialist services: parents are known to be more comfortable to be in settings made up of people with whom they can identify (Ely, Wilson and Phillips, 1998; McGaw, 2000).

- Where services are open to learning from the parents: rather than trying to fit them into a particular model, there needs to be recognition that parents themselves are best placed to identify their own needs.

5.10 Key findings

Key findings from this section are presented below, including the learning from the section which highlights features of effective support for parents with intellectual disability:

Parenting and intellectual disability

- Research from a number of countries has demonstrated that there is an increasing number of parents with learning disabilities in contact with services.

- Llewellyn and McConnell (2005) identified key lessons based on their research with parents with learning disabilities including the heterogeneity of parents with intellectual disability; the predictable challenges they face related to the intellectual disability label (e.g. low expectations about their abilities, difficult personal and socio-economic circumstances) and finally their shared achievements, and resilience in the face of hardship, as well as their efforts to demonstrate their ability to do things 'normally'.

- Tools for identifying parents with learning difficulties have been developed.

- A consistent finding from the literature is that mothers with intellectual disability typically experience poverty and hardship in raising their children (McConnell et al., 2003b). They are usually socially isolated and consequently lack the supports necessary to escape psychological stress.

Family and social support networks

- The centrality of family members in the support networks of mothers with intellectual disability emerged. Despite the development of formal support services, assistance from extended family continued to be crucial in determining whether or not mothers with intellectual disabilities retained custody of their children. This assistance typically came from female relatives, and involved practical and emotional assistance, as

well as advocacy. The authors concluded that the establishment of services did not diminish the importance of support from extended family networks (Traustadottir & Sigurjonsdottir, 2008).

- Involvement of family members has been found to be inhibited in certain situations; for example, instances were reported in one study where interested families had not been informed when major decisions were made about children, including cases of abortion and adoption (Tarleton et al., 2006).

- Good practice was identified where the involvement of the wider family is supportive or 'protective' (Barlow, 1999) and where the parent can retain control.

- The mobilisation of community supports, including the extended family, has been shown to be vital (Booth and Booth, 1995a). Services need to actively assist parents to become part of their local community (McConnell et al., 1997). A number of strategies for involving extended families have been identified (Tarleton et al., 2006).

- Research has shown that mothers with intellectual disability are isolated from their local communities and are potentially vulnerable if a breakdown occurs in the support provided by families (Llewellyn and McConnell, 2002).

- Research has demonstrated that the stress levels of parents with intellectual disability were very high, compared to the general population, and their self-reported need for social support was also high. Feldman et al. (2002) also observed that the parents with intellectual disability's perception of supports was more important than the actual amount of support provided in shielding them from the negative effects of stress.

- The studies reviewed suggested that one way of improving the outcome for parents with intellectual disability would be to help them build positive social networks.

Professional and training supports

- It has been recognised that parents labelled with intellectual disability need flexible support, varying in intensity, and provided over a long period of time (McConnell, 1997, Tarleton et al., 2006).

- Accessible information is crucial to help parents and where possible should include easy-to-read leaflets, information on tapes/DVDs, fully accessible websites, and opportunities to talk to people face to face about services. Information about universal and specialist services should be made available in places where they will be seen by parents, such as GP surgeries, day centres, colleges, and supported housing (DH and DfES, 2007).

- Services need to take into account the special learning needs of parents when designing and implementing programs involving providing opportunities for repetition, for demonstration, for learning to take place in the natural setting; the requirement for suitable teaching resources for people with little or no literacy skills as well as the involvement of parents in selecting and setting personal parenting objectives (McConnell et al., 1997).

- Support workers and professionals working with parents with intellectual disability should have some specialised training and supervision to ensure that they are sensitive and responsive to the difficulties and barriers faced by parents (Ely et al., 1998).

- Assigning a worker with a genuine liking for the family is essential (Booth and Booth, 1995a; 1994). Workers having an understanding of the families' point of view, which is not seen as interfering, has been highlighted as important (Booth and Booth, 1994).

- The recognition of the emotional needs of parents with intellectual disability is crucial (Booth and Booth, 1994).

- As intellectual disability is a difficulty in learning, one of the important roles of support workers is an educative one (Llewellyn

et al., 1997), ensuring that all aspects of support are provided at a level that the parent understands (McConnell et al., 1997).

- Clear and coordinated referral and assessment procedures between health and social care providers are vital in order to recognise support needs at an early stage of parenting and to anticipate needs that might arise at different stages of family life. Adult and children's services, and health and social care providers, should agree protocols for referrals, assessments and care pathways to respond appropriately and promptly to both the parents' and their children's needs.

- Families that are affected by parental learning disabilities may benefit from many types of service including support in using universal antenatal and postnatal services, parent groups, courses in parenting skills, counselling and family planning services (DH and DfES, 2007).

- Long-term support should be provided where necessary (DH and DfES, 2007); for example, practical support that is sustained over the longer term and directed towards reinforcing and developing parents' own skills (Booth and Booth, 1995a).

- Self-advocacy support should be made available to parents to help build confidence and self-esteem, and to prevent parenting problems such as poor hygiene or failure to attend mother and baby groups (DH and DfES, 2007).

- Provision of independent advice or advocacy: without independent advocacy support for parents, the negative views held by some practitioners about the parenting abilities of people with learning difficulties make actions and decisions that are detrimental to their interests more likely (Booth and Booth, 1995a: 301). According to Baum and Burns (2007), women with learning disabilities are often ambivalent about the whole idea of support, because they have often experienced it as reinforcing their negative social identities. It is important, therefore, that mothers

are presented with information by someone that they trust. The work of an advocate is useful to assist a woman with intellectual disability in that there is an independent person acting on her behalf, who will keep her fully informed throughout the process.

6.0 Discussion and conclusions

6.1 Introduction

Based on the literature reviewed in this report, this section will provide an overview of the current gaps that exist in legislation and structures and support mechanisms in relation to women with intellectual disabilities and pregnancy. This section will also present good policy and practice evidence on this topic from other jurisdictions.

The area of sexual and personal relationships is one of the most valued parts of a person's life. But it is in this domain that in the past excessive control has been exerted on persons with intellectual disability, either by failing to recognise this aspect of a person's being or by limiting the opportunities available to people to express their sexual selves. The current legislative framework in Ireland governing this area is weak, and it has been recognised that reform is long overdue in the area of legal capacity relating in particular to sexual relations and consent to medical treatment.

The review of literature demonstrated that research on the issue of women with intellectual disability experiencing crisis pregnancy is limited; only one study specifically on this topic emerged from Australia (Burgen, 2008). The literature, therefore, does not differentiate between crisis and non-crisis pregnancy for women with intellectual disabilities. As noted in the introduction, not all pregnancies experienced by women with intellectual disabilities are experienced as a crisis; however, a pregnancy may be perceived as a crisis by family members and/or carers, due in part to the negative impact current protective legislation (Section 5 of the Criminal Law (Sexual Offences) Act, 1993) has on attitudes to sexual relations between persons with an intellectual disability. Section 5 of the 1993 Act, in effect, criminalises sexual relations between two adults with intellectual disability (that come within the definition of impairment) who are not married and therefore, understandably, creates fear and apprehension amongst carers and family members that they may be in danger of facilitating a criminal offence.

The review examined national and international legislation - falling under civil and criminal law - relevant to women with intellectual disabilities' experience of sexual relations and pregnancy. Legislation relevant to specific decisions and tests of capacity was explored, i.e. capacity to consent to medical treatment and, in particular, to contraceptive treatment and capacity to consent to sexual relations.

There is a history of civil law cases relating to capacity to consent to medical treatment and much research on decision making capacity has concerned consent to treatment. Meanwhile, it has been observed that there has been far less consideration of capacity in the context of consenting to sexual relationships (Murphy, 2003). For example, there is no specific test designed to cover capacity to consent to sexual relations in the context of the civil law concerning a person's private rights to enter into voluntary relationships (BMA and the Law Society, 2004). Capacity to consent to sexual relations arises in the context of the provisions available in criminal law to protect vulnerable people from potentially abusive relationships.

6.2 Assessment of capacity to consent to contraceptive treatment

In Ireland, the Scheme of Mental Capacity Bill 2008 sets out the various provisions relating to assessing capacity of vulnerable people to make specific decisions, excluding capacity to consent to have sexual relations. The legislation is relevant to this topic in relation to the assessment of capacity to make medical treatment decisions, i.e. decisions about contraception, including sterilisation.

6.3 Gaps in relation to assessment of capacity to make healthcare decisions

Gaps in the current draft legislation and procedures in relation to assessment of capacity to make healthcare decisions include the following:

- Where an adult does not have the capacity to consent to or refuse medical treatment, it is common medical practice in Ireland to have their next of kin sign a consent form in relation to the treatment (LRC, 2005). This practice has no legal standing. This vacuum in the law could produce a situation where the right of a woman with intellectual disability to make decisions about her

own body, including contraceptive treatment, is superseded. If medical treatment is carried out without consent, this has implications under the Constitution, human rights law, the law of torts and criminal law (LRC, 2005). Meanwhile, some treatment decisions are so serious as to require the Courts to make them; therefore, the draft Scheme of Mental Capacity Bill 2008 provides that a decision about a non-therapeutic sterilisation in the case of a person who lacks decision-making capacity can only be made by the High Court.

- Lack of proper legal structures in this area requires health professionals to use their personal judgement in assessing capacity and in determining how to proceed if it is assessed that the person in question lacks the capacity to make a healthcare decision.

- In the context of informal decision-making and the provision of protection from liability for those providing healthcare and treatment the legislation should include a special provision requiring health professionals to obtain the consent of the 'person responsible' for the person lacking capacity, in effect to include the family members or carers of a person lacking capacity in treatment decisions (Donnelly, 2008).

- There is no provision relating to advocacy in the draft Bill, either at the individual level, through the appointment of personal advocates, or at a policy level, through the inclusion of an advocacy requirement among the functions of the Office of the Public Guardian (Donnelly, 2008). (There is provision for legal representation.)

- A requirement that the person lacking capacity should be consulted regarding the choice of personal guardian should be included in the legislation.

A number of issues have been identified (Donnelly, 2008) that require detailed guidance in the form of a Code of Practice, which should accompany legislation in this area. These include:

- The proposed definition of capacity is too open-ended; decision-makers have very little guidance in developing and applying the test for capacity in individual cases.

- Interpretation of the principles within the Scheme of Mental Capacity Bill 2008, and their application in practice; for example, Principle (c) states that 'a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success'. [91] While the intention here is to provide supported decision-making, the kind and level of support people will need to help them make a decision needs further guidance.

- Further guidance is needed on what should be considered when trying to work out the best interests of a person who lacks capacity to make a particular decision.

6.4 International good practice in capacity assessment

Elements of good practice in assessing capacity to consent to treatment were identified from other jurisdictions:

- A functional approach to assessment of capacity (used in most jurisdictions), where capacity is decision-specific and time-specific rather than global or permanent. Before any declaration of incapacity, consideration needs to be given as to whether it would be possible either to improve the person's relevant functional abilities and/or to simplify or otherwise amend the situation to improve the person's capacity.

- Entitlement of people to receive information that is appropriate, relevant and through such channels as enable them to make a decision about their healthcare. The right to comprehensible

91 See Section 2.5.1 for a full list of the Guiding Principles in the Scheme of Mental Capacity Bill.

information is contained in legislation (e.g. S. 3 (2) of the UK Mental Capacity Act, 2005).

- Emphasis on exploring the particular line of reasoning employed by the person in making decisions, and whether or not those decisions are consistent with a personal belief system, known values and reality.

- The requirement in legislation that an assessment of capacity is carried out before any care or treatment. The more serious the decision, the more formal the assessment will need to be.

- Provision of safeguards in legislation, e.g. it cannot be decided that somebody lacks capacity based on their age, appearance, condition or behaviour alone.

- Provision for an advocacy structure within legislation.

- The introduction of a legal duty to consult with others involved in caring for a person or interested in his/her welfare before carrying out acts in relation to a person who lacks capacity (Mental Capacity Act, 2005, England and Wales).

- The introduction of a standard assessment protocol (contained in a code of practice/guidelines), which would reduce bias and introduce consistency in the way that mental capacity assessments are conducted.

- The need to recognise the heterogeneity of people with intellectual disabilities in any assessment of capacity.

- A requirement in legislation that where a person lacks capacity people follow certain steps to help them work out whether a particular act or decision is in a person's best interests.

6.5 Capacity to consent to sexual relations

A finding that a person lacks capacity results in a restriction or removal of fundamental human rights and therefore the issues of capacity and rights are inextricably linked (LRC, 2005).

6.6 Gaps in Irish legislation governing capacity to consent to sexual relations

Gaps in current legislation and structures identified from the literature included:

- Section 5 of the Criminal Law (Sexual Offences) Act 1993 fails to recognise the lived experience of persons with an intellectual disability who are in consensual sexual relationships. Section 5 prohibits sex with people with 'mental impairment', who are deemed unable to consent to sex. Thus it is an offence to engage in sexual intercourse with a person with an intellectual disability (that comes within the definition of mental impairment) even if the person consents.

- Fear of facilitating the commission of a criminal offence on the part of parents and carers may prevent relationships between two adults with intellectual disability developing even where they have capacity to consent and there is no element of exploitation (LRC, 2005).

- Section 5 of the 1993 Act is an example of a diagnostic approach to consent, where a person's capacity to make a specific decision is deemed inadequate because they have a certain level of intellectual disability.

- The definition of 'mental impairment' in the legislation is inadequate: the test of ability to guard against serious exploitation (the second test in Section 5 (5) of the 1993 Act) was considered to be a better yardstick of capacity to consent rather than ability to lead an independent life (the first test in Section 5 (5) of the Act) (LRC, 2005).

The difficulty in designing legislation that would provide for a balance between the need to protect vulnerable individuals from exploitation and the need to respect an individual's autonomy and capacity to engage in voluntary and freely chosen relationships has been recognised (LRC, 2005). The literature examines various standards for determining capacity to consent to sexual relations ranging from a lower standard of understanding the sex act to a higher standard of understanding the sexual act and its consequences, such as pregnancy. However, there is no consensus in the literature on what level of understanding is required for a person to be able to consent to sexual relationships.

6.7 International good practice in assessing and promoting informed consent to sexual relations

Elements of good practice from other jurisdictions need to be explored in order to understand what informed consent to sexual relations involves.

- McCarthy and Thompson (2004) proposed that the conditions which should exist for free choice include the following:
  - For valid consent to sex, women with learning disabilities must know that sex, especially when initiated by a more powerful person, is not required and compulsory.
  - People must have sufficient communication skills to be able to make their choice (to engage in sexual activity or not) known to the other party. This means that either verbally or through an alternative communication system known to both parties, to give/deny/withdraw consent at any stage in the activity. Silence or non-communication must not be interpreted as consent.
  - There needs to be a reasonable degree of equality between the parties, so that both parties have sufficient power to make the choice to engage or not engage in sex, without fear of adverse consequences.

- The Sexual Offences Act 2003 in England and Wales defines capacity to consent in terms of ability to refuse and adopts a functional approach where an individual needs to understand the nature and consequences of the act and be able to communicate her/his choice.

- A number of commentators have concluded that an appropriate test of capacity to consent incorporates understanding of the nature of the sexual act and of the consequences of sexual activity. Adequate sex education for people who do not understand the consequences of sex would also support more autonomous decision-making.

- A positive development towards striking a balance between sexual rights for people with intellectual disabilities and protection from exploitation incorporates taking into account the situational aspect of capacity, where people with intellectual disabilities may be able to give their consent to sexual relationships with certain persons, but not with others. An example of this is contained in Sections 34 -37 of the Sexual Offences Act, 2003, i.e. offences where the person's agreement to engage in sexual activity is secured through an inducement, threat or deception (see Sections 3.12.1 and 3.14 above).

- Laws which prohibit specific sexual relationships have been introduced in a number of countries, prohibiting sexual activity with women with intellectual disabilities by those in positions of power, e.g. health professionals, workers in a residential facility, care workers. Under these laws capacity is not an issue; they apply regardless of whether or not the woman consented to taking part in sexual activity.

6.8 Practice considerations – supports and services

Research has highlighted the following good practice provisions in supports and services for women with intellectual disability:

- Standardised procedures to inform assessment of capacity to consent to medical treatment and sexual relations need to be developed and should adopt a functional approach.

- Women with intellectual disability should be supported as much as possible to make their own choices.

- Research has demonstrated that the contraceptive and gynaecological needs of the intellectually disabled population do not differ widely from those of the general population. It is essential, therefore, that the health needs of women with intellectual disability be viewed from the perspective of current standards of care and management while making adjustments to match individuals' needs, abilities and other medical conditions (Grover, 2002).

- Several authors stressed that longer consultation times are required in the care of women with intellectual disability; this has implications for resources in terms of time and personnel costs.

- Access and referral by GPs to appropriate education and resources (Grover, 2002).

- Women with intellectual disabilities should be supported to have access to appropriately trained family planning professionals for counselling regarding the need for, and method of, contraception treatment prior to its use. People may require more than one session of advice and information.

- Agencies providing support and advice should be encouraged to produce information in accessible formats for people with intellectual disability (under the Equal Status Act 2000-2008, they are obliged to provide reasonable accommodation to people with disabilities (subject to exception).

- An individualised, person-centred, multidisciplinary approach that incorporates caregivers, medical staff, educators, and the individual should be used to provide comprehensive sexual health care to persons with intellectual disability (Servais et al., 2002).

- Good practice involves integration of services where procedures, criteria and pathways are confirmed between maternity services and children's and adults' social care services, and, for example, between GPs and intellectual disability services.

- During the early stages of pregnancy in particular, good practice occurs when GPs, community midwives and health professionals work closely alongside parents (as part of a core team of professionals across learning disabilities and children's specialisms).

- Research shows that the earlier services can get involved, the better the outcomes for the family. Early identification of needs is crucial and should start when pregnancy is confirmed.

- Early referral to the necessary support services is crucial, particularly for women who have been sexually abused.

- The close connection between the promotion of capacity to consent and the provision of sex education was stressed in the literature. Adequate and appropriate sex education should involve on-going access to sex education (as opposed to the 'one shot' variety), particularly with regard to sexual health and pregnancy, contraception, safe sex, abuse, and some aspects of the law (such as consent). Other factors of effective sex education are detailed in Sections 4.3 and 4.3.1.

- As women with intellectual disability have difficulty in accessing, understanding and applying popular literature and materials on pregnancy and parenthood, they need specialist support to access antenatal services appropriately.

- In the UK, a number of tools for identifying parents with learning disabilities have been developed to help staff identify whether a person has a learning difficulty (see Section 5.3).

- The literature notes that it is essential to raise awareness of parents with learning disabilities' support and communication needs with generic services such as antenatal provision, midwifery, health visiting, and child social work. In the UK context, professionals from specialist adult learning disabilities'

teams are best placed to do this by acting as a source of expertise for mainstream services.

- The following adaptive methods and communication aids were recommended to effectively support people with intellectual disability in their decision-making: avoiding complicated language; use of repetition, pictures, role play; audio-taping consultations; availability of clearly illustrated educational resources written in plain language; and health and social care professionals being conscious of not talking solely to the parents/caregivers, but speaking directly to the patient.

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Appendices

Appendix A – Consent Form 4

Form 4

Good Practice in Consent Implementation Guide, Department of Health, UK

Consent Form 4

Form for adults who are unable to consent to investigation or treatment to be retained in patient's notes

Patient details (or pre-printed label)

Patient's surname/family name

Patient's first names

Date of birth

Responsible health professional

Job title

NHS number (or other idetifer)

Male ☐ Female ☐

Special requirements

Male ☐ Female ☐

Male ☐ Female ☐

(eg other language/other communication method)

Form 4

Patient identifier/label

All sections to be completed by health professional proposing the procedure

A Details of procedure or course of treatment proposed

(NB see guidance to health professionals overleaf for details of situations where court approval must first be sought)

B Assessment of patient's capacity

I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because:

- ☐ the patient is unable to comprehend and retain information material to the decision; and/or
- ☐ the patient is unable to use and weigh this information in the decision-making process; or
- ☐ the patient is unconscious

Further details (excluding where patient unconscious): for example how above judgements reached; which colleagues consulted; what attempts made to assist the patient make his or her own decision and why these were not successful.

C Assessment of patient's best interests

To the best of my knowledge, the patient has not refused this procedure in a valid advance directive. Where possible and appropriate, I have consulted with colleagues and those close to the patient, and I believe the procedure to be in the patient's best interests because:

(Where incapacity is likely to be temporary, for example if patient unconscious, or where patient has fluctuating capacity)

The treatment cannot wait until the patient recovers capacity because:

Form 4

D Involvement of the patient's family and others close to the patient

The final responsibility for determining whether a procedure is in an incapacitated patient's best interests lies with the health professional performing the procedure. However, it is good practice to consult with those close to the patient (eg spouse/partner, family and friends, carer, supporter or advocate) unless you have good reason to believe that the patient would not have wished particular individuals to be consulted, or unless the urgency of their situation prevents this. "Best interests" go far wider than "best medical interests", and include factors such as the patient's wishes and beliefs when competent, their current wishes, their general well-being and their spiritual and religious welfare.

(to be signed by a person or persons close to the patient, if they wish)

I/We have been involved in a discussion with the relevant health professionals over the treatment of (patient's name). I/We understand that he/she is unable to give his/her own consent, based on the criteria set out in this form. I/We also understand that treatment can lawfully be provided if it is in his/her best interests to receive it.

Any other comments (including any concerns about decision)

Name

Relationship to patient

Address (if not the same as patient

Signature Date

If a person close to the patient was not available in person, has this matter been discussed in any other way (eg over the telephone?)

Male Female

Details:

Form 4

Signature of health professional proposing treatment

The above procedure is, in my clinical judgement, in the best interests of the patient, who lacks capacity to consent for himself or herself. Where possible and appropriate I have discussed the patient's condition with those close to him or her, and taken their knowledge of the patient's views and beliefs into account in determining his or her best interests.

I have/have not sought a second opinion.

Signature

Date

Name (PRINT)

Job title

Where second opinion sought, s/he should sign below to confirm agreement:

Signature

Date

Name (PRINT)

Job title

Guidance to health professionals (to be read in conjunction with consent policy)

This form should only be used where it would be usual to seek written consent but an adult patient (18 or over) lacks capacity to give or withhold consent to treatment. If an adult has capacity to accept or refuse treatment, you should use the standard consent form and respect any refusal. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of Part IV of the Mental Health Act 1983, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has clearly refused particular treatment in advance of their loss of capacity (for example in an advance directive or 'living will'), then you must abide by that refusal if it was validly made and is applicable to the circumstances. For further information on the law on consent, see the Department of Health's Reference guide to consent for examination or treatment (www.doh.gov.uk/consent).

When treatment can be given to a patient who is unable to consent

For treatment to be given to a patient who is unable to consent, the following must apply:

- the patient must lack the capacity ('competence') to give or withhold consent to this procedure AND

- the procedure must be in the patient's best interests.

Capacity

A patient will lack capacity to consent to a particular intervention if he or she is:

- unable to comprehend and retain information material to the decision, especially as to the consequences of having, or not having, the intervention in question; and/or

- unable to use and weigh this information in the decision-making process.

Before making a judgement that a patient lacks capacity you must take all steps reasonable in the circumstances to assist the patient in taking their own decisions (this will clearly not apply if the patient is unconscious). This may involve explaining what is involved in very simple language, using pictures and communication and decision-aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates or supporters.

Capacity is 'decision-specific': a patient may lack capacity to take a particular complex decision, but be quite able to take other more straight-forward decisions or parts of decisions.

Best interests

A patient's best interests are not limited to their best medical interests. Other factors which form part of the best interests decision include:

- the wishes and beliefs of the patient when competent
- their current wishes
- their general well-being
- their spiritual and religious welfare.

Two incapacitated patients, whose physical condition is identical, may therefore have different best interests. Unless the patient has clearly indicated that particular individuals should not be involved in their care, or unless the urgency of their situation prevents it, you should attempt to

involve people close to the patient (spouse/partner, family and friends, carer, supporter or advocate) in the decision-making process. Those close to the patient cannot require you to provide particular treatment which you do not believe to be clinically appropriate. However they will know the patient much better than you do, and therefore are likely to be able to provide valuable information about the patient's wishes and values.

Second opinions and court involvement

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient's condition prevents this. Donation of regenerative tissue such as bone marrow, sterilisation for contraceptive purposes and withdrawal of artificial nutrition or hydration from a patient in PVS must never be undertaken without prior High Court approval. High Court approval can also be sought where there are doubts about the patient's capacity or best interests.

Appendix B - Sex Education Resources for People with Intellectual Disabilities

CHANGE, an organisation based in the UK has produced a range of illustrated accessible publications on parenting, including **Planning a Baby and You** and **Your Baby** (Affleck & Baker, 2004), as well as a CD Rom of pictures from the **You and Your Baby** book. CHANGE has recently received funding to produce a further accessible book: **My Pregnancy, My Choice,** covering pregnancy and birth. Further information on these resources is available at www.changepeople.co.uk

The Family Planning Association (fpa) in the UK produce a number of sex education resources for use with people with learning disabilities including **All About Us** – a CD Rom aiming to assist the personal development and knowledge of people with learning disabilities around sex, sexuality and relationships; and the **Talking Together** series for use with young people with learning disabilities, covering the topics of contraception, and sex and relationships. Resources available from the Family Planning Association's website: www.fpa.org.uk

Family Planning, New South Wales: One of the most popular resources is **Love and Kisses**, produced in 2007, a DVD showing a compilation of interviews of people with intellectual disabilities telling their own stories about their reproductive and sexual experiences. Information on other resources available at http://www.fpnsw.org.au/disability/

McCarthy, M. And Thompson, D. (1998) **Sex and the 3Rs: Rights, Responsibilities and Risks**. A sex education package for working with people with learning difficulties. Brighton: Pavilion
This kit provides material aimed at teaching sex education for people with learning difficulties. Topics include appropriate and inappropriate sexual behaviour, sexual abuse, safe sex and contraception. The kit contains teaching notes and explicit line drawings.

South East London Health Promotion Services (1992) **My Choice, My Own Choice**. A Sex Education Video for People with Learning Disabilities. Brighton: Pavilion Publishing

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