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Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood

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While the National Disability Authority (NDA) has commissioned and funded this research, this was a joint initiative between NDA and the National Women's Council of Ireland (NWCI). A Steering Group composed of members from the NDA, the NWCI, the Health Service Executive and the Crisis Pregnancy Agency provided advice and guidance to the research team. Responsibility for the research (including any errors or omissions) remains with the School of Nursing and Midwifery, Trinity College Dublin. The views and opinions contained in this report are those of the authors and do not necessarily reflect the views or opinions of the NDA or the NWCI.

Executive Summary

1. Introduction

This review was commissioned by the National Disability Authority (NDA), in a joint initiative with the National Women's Council of Ireland (NWCI), to provide information on the challenges facing women with disabilities in accessing health services during pregnancy, childbirth and early motherhood, both in Ireland and internationally. The review is one of 3 documents meeting the objectives of a national study commissioned by the NDA. The second report (Begley et al, 2009) presents a comprehensive review of Irish and international social policies relating to disability and childbirth. The third document (Begley et al, 2010) presents the results of a nation-wide study exploring the strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood.

2. Background

Over the past 2 decades, childbirth in Ireland has become more medicalised, and women with disabilities may therefore be at risk of being viewed through a medical lens solely because of their particular disability. A review of the salient international literature relating to the care of women with all types of disabilities showed a history of discrimination. Evidence from the literature suggests that society has undervalued women with disabilities, has exerted control over their sexual and reproductive lives and, in many cases, has exacerbated their difficulties. Mothers with intellectual disabilities or mental health difficulties, in particular, are often separated from their children, whether or not there is any evidence of potential harm or neglect.

3. Purpose of review

The purpose of this review was to identify and analyse Irish and international literature on the challenges facing women with disabilities in accessing health services during pregnancy, childbirth and early motherhood. Because the remit of the literature review was to look at the challenges facing women in this situation, there may appear to be a rather negative slant to the report. This is neither intentional nor accurate and, indeed, some positive factors are reported under the heading of ‘facilitators’ to access.

4. Outline of review

To provide a background and context for the review, a search for literature on historical developments in the care of women with disabilities, their sexuality and reproductive rights, and the effect of disabilities on pregnancy was conducted. In addition, and to cover the main focus of this review, literature on the challenges faced by women with disabilities in accessing services during pregnancy, childbirth and early motherhood was sought and presented under the headings of ‘barriers’ and ‘facilitators’ to access.

A total of 161 papers on women with physical disabilities were sourced, 114 of which were relevant; 18 papers (14 of which were relevant) on women with hearing impairment, 9 (6 of which were relevant) on women who had a visual impairment, 3 papers on ethnicity and disability, 97 on women with mental health difficulties and 52 on women with intellectual disability. The review included both qualitative and quantitative research papers from 1950 to 2008. Data from countries comparable to Ireland were included and all literature from an Irish context was used.

A total of only 87 research papers relating to barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood were identified for women with all disabilities, although some papers discussed more than one disability. These papers were reviewed and analysed under 5 component headings that define ‘access to services’: availability, accessibility, accommodation, affordability and acceptability. The review did not consider access of women with disabilities to general health services, personal assistance and care issues, the effects of poverty and social exclusion, or women and disability in general as the NDA has previously commissioned reviews in these areas. All research referred to in this document is disability-specific and throughout the report the term ‘women’ refers to women with disabilities unless otherwise stated.

5. Key research findings

The key findings from this review of Irish and international literature were:

5.1. General findings

- Maternity care in Western society has become increasingly medicalised, which has led to a diminution of emphasis on the importance of women’s experiences during pregnancy and childbirth.
- Sixty-three percent of a sample of 500 mothers from the general population in Ireland were unhappy with aspects of their care during pregnancy or birth.
- In Ireland, approximately 38,000 females between the ages of 18 and 44 years have a disability of some type.
- Evidence from the literature suggests that society has, in many instances, undervalued women with disabilities and the care of women with all types of disabilities shows a history of discrimination that lasts to the present day.
- It would appear from the literature that society has exerted control over the sexual and reproductive lives of women with disabilities and, particularly in the case of mothers with intellectual or mental health disabilities; there is often a presumption of risk to the child whether or not there is evidence of such risk.

- Adverse societal attitudes such as these may very well lead to barriers for women with disabilities in accessing suitable services in pregnancy, childbirth or motherhood.

5.2. Findings in relation to women with physical disabilities

Barriers for women with physical disabilities were found in relation to:

- accessibility, related to the location and models of care, difficulties in transport and moving around the physical environment
- accommodation, centred mainly around the lack of provision of suitable health information and less so around difficulties with communication
- acceptability, in terms of lack of knowledge and negative attitudes and behaviours from staff.

Facilitators to access for women with physical disabilities were more difficult to ascertain from the published literature, but some were found in relation to:

- accessibility, relating to improving access to buildings and services, with some emphasis on developing ease of movement around the physical environment
- accommodation, focussing on the provision of sensitive antenatal education classes
- acceptability, noting that considerable work on developing health professionals' knowledge of, and attitudes towards, physical disability is required.

5.3. Findings in relation to women with sensory impairments

Barriers for women with sensory impairments were found in relation to:

- accessibility, which focussed mainly on the difficulties of orientation to the health care setting, completing registration forms, locating a seat in the waiting area, and realising when to go into the examination room
- accommodation, which centred mainly around communication and health education, where women with hearing impairment, in particular, were at a great disadvantage

- acceptability, which related to how women with sensory disabilities tend not to feel respected or supported and have reported that some health professionals fail to recognise and appreciate their needs.

Facilitators suggested in the published literature to improve access for women with sensory impairments were slight, but some were found in relation to:

- accessibility, including the use of telephone amplifiers and/or pictorial signage, Braille, audible, visual and tactile systems in waiting rooms and information provided in an appropriate language and format
- accommodation, focussing on the need for extended consultation times and culturally sensitive antenatal education classes
- acceptability, relating to disability awareness and training for health professionals, particularly in speaking correctly for lip-readers, and in the use of basic sign language; education of health professionals should perhaps incorporate education by women with disabilities themselves.

It was also found that the employment of sign language interpreters in the appropriate languages is useful for women with sensory loss who are from ethnic minority groups.

5.4. Findings in relation to women with mental health difficulties

Barriers for women with mental health difficulties appeared to be considerably greater, or perhaps were better documented, than for women with other disabilities, and were found in relation to:

- availability of appropriate care, as there are poor links between maternity and mental health services
- accessibility, in relation to women's mental state, as they may lack motivation to attend clinics or may even, rarely, deny the pregnancy totally
- accommodation, where the women's considerable needs included lack of knowledge of the existence of mental difficulties in pregnancy and the postnatal period, and of the services available to them; lack of knowledge

of maternity care professionals about mental health issues; and poor screening practices
- acceptability, centred mainly around a reluctance to disclose their illness and distress, due to society's, and their family's, stigmatisation of mental health problems; fear of being judged a 'bad mother'; losing custody of their child; taking medication that might affect the fetus or baby while breast-feeding, or impair their ability to care for their children; lack of trust in health care providers and the feeling that they are continually having to prove themselves to the authorities
- affordability, as many are from low income families and cannot afford to pay for costs of childcare and transport, which may prevent them from accessing health care services.

Few facilitators to improve access for women with mental health difficulties were mentioned in the literature, but some were found in relation to:

- availability, by providing training and education of health professionals to improve communication between professionals in maternity services and those in mental health care; through introducing telesupport or web-based support groups; by providing designated perinatal multidisciplinary teams in the community, including psychologists and social workers, and specialist mother and baby psychiatric units
- accessibility, in particular encouraging health professionals to develop more trust with their clients
- accommodation, noting the need to provide education for women about mental illness and the services available to them and to provide support groups
- acceptability, where training and education of health professionals and family meetings were suggested as a means to decrease the negative attitudes encountered; through supportive partnerships between women and health professionals where they would be treated with respect, and their strength acknowledged; relating to the need for continuity of care, help in communicating with their children, and more counselling services

instead of drugs (with non-national women preferring counsellors from their own cultural background)

- affordability, regarding the provision of childcare facilities at clinics and practical help with mothering.

5.5. Findings in relation to women with intellectual disabilities

Barriers for women with intellectual disabilities were found in the literature in relation to:

- society's negative attitudes to women with intellectual disabilities becoming pregnant, and caring for their children, with a resulting lack of support networks for women with intellectual disability during pregnancy, childbirth and early motherhood;
- conservative and protective perspectives from frontline caring staff and parents regarding the sexuality of women with intellectual disability, which put the women at risk of coercive sterilisation or forced contraception.

While the Disability Act (Government of Ireland, 2005) places statute-based obligations on public bodies to provide accessible services and information, research on facilitators to access to maternity services for women with intellectual disabilities was almost non-existent.

6. Key research gaps

It is recommended that all future research in the area of women's health should include women with disabilities, as appropriate. Through this review, research gaps were identified in the following areas in relation to general maternity and health service care and in relation to women in the 5 categories of disability.

6.1. General maternity and health service care

- The attitudes of society in relation to women with disabilities, in particular in relation to their sexual and reproductive lives and the issue of taking custody of their children.

6.2. Research on the care of women with any of the disabilities during pregnancy, childbirth and early motherhood

Research gaps have been identified in the areas of:

- locations and models of maternity care for women with any disability
- transport difficulties experienced by these women
- the physical environment in maternity hospitals and its effect on women with any disability
- the provision of health information for these women
- knowledge, attitudes and behaviours of health care staff towards women with any disability
- the adequacy of consultation times between women with disabilities and health care professionals.

6.3. Research on the care of women with specific disabilities during pregnancy, childbirth and early motherhood

In addition, research gaps have been identified in the area of:

- communication needs for women with sensory impairments when accessing the maternity services
- the links between maternity and mental health services
- the motivation of women with mental health difficulties to attend clinics
- women’s knowledge of the existence of mental health difficulties in pregnancy and the postnatal period and of the services available to them
- knowledge of maternity care professionals about mental health issues
- screening practices for mental health difficulties in pregnancy and the postnatal period.

Some of the above research gaps are addressed by parts 2 and 3 of this study commissioned by the NDA to review social policy documents in relation to women with disability and to explore the strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood.

6.4. Research on the care of women with intellectual disabilities during pregnancy, childbirth and early motherhood

Due to the lack of comprehensive investigative work concerning maternity care for women with intellectual disabilities, an extensive programme of exploratory research is required to ascertain their views and experiences as they journey through pregnancy, childbirth and early motherhood. This can then be followed on by research targeted at developing specific aspects of care identified as lacking or below quality. The first stage of this exploratory work was conducted as one section of part 3 of this study commissioned by the NDA.

7. Conclusion

The National Disability Authority and National Women's Council of Ireland have previously highlighted the need to improve access to reproductive and sexual health services for women with disabilities in Ireland, as well as the need for disability awareness training among health professionals (NWCI, 2001; NDA, 2007). Evidence from the NDA's second national survey suggests that people's attitudes towards disability are improving (NDA, 2007) but it is apparent that a number of inequalities for women with disabilities still exist. The literature presented here corroborates that view and emphasises the need to improve the care services for women with disabilities attempting to access health care during pregnancy, childbirth and early motherhood.

The dearth of literature in this review from the Irish perspective highlights the need for research in this area, and emphasises the importance of the current study commissioned by the National Disability Authority, of which this review forms the first part. The second part, which leads on from and is complementary to this report, is a review of Irish and international social policies relating to disability and childbirth (Begley et al, 2009). These 2 documents demonstrate a need for comprehensive policy development and planning in consultation with women with disabilities to provide an improved response to the maternity service needs of this group.

The starting point for any change in service provision has to be with the individuals seeking that service (Kennedy and Murphy-Lawless, 2002), so if access to health services during childbirth, pregnancy and early motherhood is to be improved for women with disabilities, their experiences must be documented. The third section of the NDA-commissioned work, therefore, sought the experiences of women with disabilities in terms of the strengths and weaknesses of publicly-funded Irish health services provided to them in relation to pregnancy, childbirth, and early motherhood, with a view to informing the development and improvement of maternity care services for women with disability in Ireland (Begley et al, 2010).

Section One: Introduction, methodology and background of review

Chapter One: Introduction

1.1. Definition of disability

There are many definitions of 'disability' (Appendix 1), but the one chosen to guide this review is the definition of the International Classification of Functioning Disability and Health: 'Disability is a decrement in functioning at the body, individual or societal level that arises when an individual with a health condition encounters barriers in the environment' (WHO, 2001). Within an Irish context the Disability Act (Government of Ireland, 2005) defines disability as 'a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment (pg. 6).'

1.2. Purpose and aims

This literature review was commissioned by the National Disability Authority in order to identify and analyse Irish and international literature on the challenges facing women with disabilities in accessing health services during pregnancy, childbirth and early motherhood. The review forms the first section of a 3-part study commissioned by the NDA. The second part is composed of a comprehensive review of current policy governing procedure and practice in service provision at the levels of the Health Service Executive (HSE), relevant professional bodies and maternity hospitals or units, for women with disabilities when accessing publicly-funded Irish health services during pregnancy, childbirth and early motherhood. It includes a comparison of the state of such policy development in Ireland vis-à-vis the international situation (Begley et al, 2009).

The third element (Begley et al, 2010) presents the results of a nation-wide study exploring the strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood. The study, which utilises semi-structured interviews, incorporates the experiences of women across the country, from all socio-economic groups, and includes their experiences of care from general practitioners, midwives, obstetricians, paediatricians, and public health nurses, as well as the maternity hospitals. Recommendations are made as to how the experience of engaging with the various publicly-funded Irish health service providers during pregnancy, childbirth and early motherhood can be improved for women with disabilities.

This review, as the introductory part of the complete study, aimed to:

- provide information on the challenges facing women with physical disabilities, visual impairment, hearing impairment, mental health difficulties or intellectual disabilities in accessing health services during pregnancy, childbirth and early motherhood
- identify the main barriers and facilitators to access experienced by these women, both nationally and internationally
- highlight research gaps that need to be addressed in future work, particularly in Ireland
- present the findings in the most appropriate manner to influence policy–making in the future.

Because the remit of the literature review was to examine the challenges facing women with disabilities in accessing health services for maternity care, there may appear to be a rather negative slant to the report, giving the impression that there is nothing positive in the literature about accessing services for this population. This is neither intentional nor accurate and, indeed, some positive factors are reported under the heading of ‘facilitators’ to access. However, the main focus has, necessarily, to be on the negative aspects that challenge women with disabilities in their quest for care.

The review did not consider in detail access of women with disabilities to general health services, personal assistance and care issues, the effects of poverty and social exclusion, or women and disability in general as the NDA has previously commissioned reviews in these areas.

1.3. Methodology

A systematic review of the literature, published in English, from 1950 to 2009 was undertaken, with reference to earlier seminal texts or texts providing a historical background, to identify the challenges that women with disabilities encounter when accessing health services during pregnancy, childbirth and early motherhood. Searches were undertaken in the major electronic bibliographic databases and a number of methods were used to identify the relevant literature:

- database searches using CINAHL, PubMed (1950-2009), Midirs, PsychoInfo, PsychoArticle, Embase, ERIC (1966-2009), Science Direct, Web of Science, Wiley inter science, Applied Social Science Index and Abstracts (1983-2009), Social Science Citation Index and Social Sciences Index (1983–2009);
- the library of Trinity College Dublin (TCD) and the National Disability Authority were hand searched for relevant books, reports and general articles e.g. The Commission on the Status of People with Disabilities;
- web-based searches on disability and health services, including websites for The Irish Government, The European Commission, The World Health Organisation (WHO), The United Nations (U.N.), and the Department of Health (DOH) websites of the Netherlands and the United Kingdom;
- a general Internet search using Google and Google Scholar search engine;

- grey literature e.g. Index to Theses of Great Britain and Ireland, unpublished reports and policy documents.

Major organisations and experts in the field were also contacted (Appendix 2). Citation searches were conducted on key papers and the reference lists of included studies were checked for additional references.

A combined free-text and thesaurus approach was adopted for key-word selection. ‘Population’ search terms included disabil*, disability, physical disability, decreased mobility, immobility, disabled person, visually impaired person, vision disorders, blind, deaf, hearing impaired, hard of hearing, intellectual disability, learning disability, developmental disability; mental retardation, mental health, mental illness, enduring mental health difficulties, severe mental illness, pre/postnatal mental illness, pre/postnatal depression, anxiety, schizophrenia, psychosis, mother and baby units, and child custody. Other key words used included: health services, maternity services, health professional, inequality, equity, barriers, access, challenges, attitudes, pregnancy, childbirth, maternity; motherhood, parenting, parents, social construct, explanation, and definition. No date, study-type or publication-type restrictions were used, apart from non English studies and those imposed by the databases searched.

1.4. Types of literature sourced

The review identified that there was a paucity of literature in relation to the challenges that women with disabilities encounter when accessing health care services during pregnancy, childbirth and early motherhood. A substantive volume of literature was sourced in relation to the debate surrounding women with disabilities, their right to reproductive technologies, and their effort to be recognised as women who can fulfil the traditional roles society affords to women. This literature, details of which are given in section 1.6 and Appendices 3-6, can be categorised into 2 distinctive types; the first is the existential lived experiences of women with disabilities while the second is formed by theoretical papers, written mainly by academics, which attempt to offer an analysis of these women's experiences (Tilley, 1998). A discussion of this body of work is presented in the second chapter of this review to provide a background and context for the substantive review.

1.5. Inclusion criteria

In the absence of any breadth of literature on women's experiences of accessing the health services during pregnancy, childbirth and early motherhood, some additional material was sourced and reviewed in relation to the experiences of people with certain disabilities accessing the general health services.

1.5.1. Quality assessment

Papers were assessed for quality and only those demonstrating rigorous empirical research findings (as assessed by unbiased sampling methods, data collection, analysis and presentation of results based on empirical data), were used in the review. Opinion pieces or news items, however, were read and included where relevant. In addition, historical texts and papers were used to provide a historical background, particularly when discussing mental health and intellectual disabilities.

1.5.2. Research domains included

The literature fell into 3 categories, the first emerging from the qualitative domain. Here face to face interviews or focus groups were the primary methods of data collection. These studies identified a multitude of environmental, structural, and process challenges encountered by women with disabilities that impacted significantly on the person's ability to access and avail of quality health care. However, the small sample sizes associated with qualitative designs means that the findings cannot be taken as representative of the entire population of people with disabilities. The second body of literature emanates from the quantitative domain. Here data are generated from probability samples participating in large, national surveys using postal questionnaires or telephone surveys. Response rates tended to be low, however, so representativeness is, again, questionable. The third category of research is of the case study variety, which tends to focus on the challenges encountered by people with a single impairment, for example, deafness or mobility/physical disabilities. Again, sample sizes are small so that findings are not always representative of the entire population with the specific impairment.

1.5.3. Social and cultural appropriateness of research

Studies that inform the review are mainly from America, Canada, Australia and the United Kingdom, as countries comparable to Ireland in terms of cultural, economic and social settings, with a very small number of studies from the Irish perspective. A few studies from other cultural settings such as China and Malaysia are mentioned when appropriate, or in the absence of literature from our own or comparable societies.

1.6. Number and type of papers selected for use in each section

The introductory background in Chapter 2, which provided a context for the review, used literature on historical developments in the care of women with disabilities, their sexuality and reproductive rights, and the effect of disabilities on pregnancy. A total of 161 papers on women with physical disabilities were sourced, 114 of which were relevant; 18 papers (14 relevant) were sourced on women with hearing impairment, 9 (6 of which were relevant) on women with visual impairment, 3 papers on ethnicity, 97 on women with mental health difficulties and 52 on women with intellectual disability. Papers relating to barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood were identified for women with all disabilities. Twenty-eight papers for women with physical disabilities, 20 referring to vision and/or hearing impairment, 23 relating to mental health disorders, and 26 in the area of intellectual disability were assessed and selected for detailed analysis and inclusion in the review. Salient facts such as aim, sample size, research approach and main findings were noted and are presented in tabular format in

Appendices 3 - 6. The main findings from papers in each category were combined and are presented in Chapters 3 to 6.

1.7. Format of the review

Chapter 1 introduces the review, sets out the aims and purpose, describes the methodology and gives an overview of the content. Chapter 2 provides the background and context for the main sections, including a brief introduction to childbirth and motherhood in Ireland. Definitions of disability and a historical background of the different disabilities and their relationship to pregnancy, childbirth and motherhood are also reported. Chapter 3 outlines the barriers and facilitators for women with physical disabilities in accessing services during pregnancy, childbirth and early motherhood. Chapter 4 describes how women with vision or hearing impairment experience barriers and facilitators in accessing these services. Chapter 5 examines the barriers and facilitators for women with mental health difficulties in accessing services and professional help during pregnancy, childbirth and early motherhood. Chapter 6 explores how women with intellectual disabilities encounter barriers and facilitators to accessing these services. A summary of key findings, with identification of the major research gaps, concludes each of these chapters. Chapter 7 provides a summary overview and Chapter 8 lists key research findings and identifies research gaps.

Chapter Two: Background and context

2.1. Introduction

This chapter provides, firstly, a brief introduction to childbirth and motherhood in Ireland. An outline is then provided of the difficulties in ascertaining information from official statistics on the number of women in Ireland with disabilities in each category of interest. Definitions are included where necessary and the historical background and context of pregnancy, childbirth and motherhood for women with physical, sensory, mental health and intellectual disabilities is given. Finally, societal attitudes to all women with disabilities are described, which may lead to barriers for women with disabilities in accessing suitable services in pregnancy, childbirth or motherhood. This chapter sets the scene for the presentation of a detailed exploration of facilitators and barriers to access of services in succeeding chapters.

2.2. Childbirth and motherhood in Ireland

The provision of maternity care, presently supplied through 20 maternity hospitals/units (19 of which are publicly-funded), catered for 64,237 births in 2006 (Central Statistics Office (CSO), 2008a). Over the past 4 decades, maternity care has become increasingly medicalised due to 3 main factors:

- A widespread provision of privatised health care for women above the poverty line, centred on consultant obstetricians as principal providers of care
- A progressive move to close down the provision of midwifery care in the community from the 1960s onwards
- A move to build centralised maternity units in large hospitals under the direction of obstetric consultants while smaller units have been closed down.

The dominant model now in use is that of consultant-led, hospitalised birth (Wagner, 2001; Devane et al, 2007), although there are in existence 2 pilot midwifery-led units and various midwifery-led initiatives such as ‘early transfer home’ and ‘Domino’[1] schemes. The increasing use of technology, characterised as technocratic birth (Davis-Floyd, 1992), and the prevalence of the ‘economic model’ of childbirth (Begley, 2002) has led to a diminution of emphasis on the importance of women’s experiences during pregnancy and childbirth, making them almost “invisible” in the process of their own pregnancy and birth (Begley and Devane, 2003).

Across many advanced societies, the movement demanding changes in maternity services towards more women-centred care, including the key tenet of choice, has grown up alongside, and in opposition to, the increasingly interventionist provision of maternity care. In the United Kingdom (U.K.), it has received serious parliamentary consideration in the last decade leading to new national policies and directives (Department of Health, 1993).

In Ireland, choice and women-centred care have been described as a minimum requirement for responsible maternity care by a recent pressure group of concerned women, midwives and maternity carers (Choices in Childbirth Initiative, 2007). Despite this, a national survey of 500 mothers (including those with and without disabilities) conducted by the Irish Examiner and Lansdowne Market Research found that 63% of women in this sample were unhappy with aspects of their care during pregnancy or birth (O’Doherty and Regan, 2006). In particular, waiting times and travelling distances to attend antenatal clinics were a cause of distress, with 20% of women in Munster forced to travel 31 miles or more to give birth (O’Doherty, 2006). It is clear that women with disabilities may thus be in an even more challenging situation.

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[1] “Domino” stands for DOMiciliary IN and Out. Women with no risk factors receive antenatal care in the community from a team of midwives, one of whom visit the woman in her own home in early labour, assists her through labour and escorts her to hospital in time for the birth. The woman and her baby may then go home again 6 hours later, if there are no complications, and they are visited by one of the team midwives daily for 5-7 days in the postnatal period.

A decade ago, Barbara Murray and Audrey O'Carroll commented that the lives of women with disabilities in Irish society remained largely hidden compared with able-bodied women (Murray and O'Carroll, 1997:pg. 494). They suggest the experience of pregnancy and child birth can change this but not necessarily in a way that fully supports and encourages the expectation that women with disabilities can undertake mothering successfully, let alone live their lives with resilience, creativity and positivity.

According to Segura (1994), society's construction of motherhood is based on studies of white, middle class women, not women of colour or less privileged women. Thus it may be hard within Irish culture to accept women with disabilities as mothers, as they differ from the norm. It may also be particularly difficult to change the institutional culture of maternity care in Ireland that has lessened women's involvement for so long, especially when coupled with other factors, such as a massive under-investment in wide-ranging midwifery services in the community.

2.3. Official statistics and definitions of disability in Ireland

2.3.1 Historical development of data collection

Official statistics on a limited range of what are now termed 'disabilities' date back to 19th century Ireland in the form of the first modern national Census of 1841. Doyle (Doyle, 2003:pg.11) lists the categories that were used up to the Census of 1911 as follows:

-Lunatics and Idiots
-Deaf and Dumb
-Dumb not Deaf
-Blind

McDonnell observes that the impetus for this classification and number-gathering reflected the perceived need to sequester ‘unfit’ people within charitable institutions and schools that would impart some sort of ‘moral’ training and occupational skills to them and so avoid their becoming a ‘burden’ on the wider society (McDonnell, 2003:pg. 29). This historical period was dominated by the ideology of the Poor Laws and the workhouse and the division between the ‘deserving’ and ‘undeserving’ poor. McDonnell relates that, with the exception of the Stewart Institution which, from its inception in 1869, did have a clear educational ethos, the common practice was to send those who were officially termed the ‘chronic and incurable classes’ (McDonnell, 2003:pg. 29) either to the workhouse or to a kind of custodial asylum. After Independence, people were sent to county homes and mental hospitals. This form of ‘disability apartheid’ was ‘carefully organised’ (Conroy, 2003:pg. 45).

Through most of the twentieth century, individual service providers and, later, local health boards did collect some data on the incidence of disability, but it was not standardised nor was it redirected into a national database. Instead there was a gap of 91 years between the 1911 Census and the 2002 Census, with no population-based enumeration of people dealing with any form of disability or impairment (Doyle, 2003:pg. 11-12).

2.3.2. Inclusion of disability statistics in national Census

In 1996, the Commission on the Status of People with Disabilities called for improved data and statistics (Commission on the Status of People with Disabilities, 1996) to enhance service planning and provision for people with disabilities. Thus, the Central Statistics Office put in place questions on disability for the 2002 Census, emerging with an overall figure of 323,707 or 8.3% of people in the state identifying themselves as having a long-lasting health problem or a disability, of which 171,901 were women (CSO, 2004a). The CSO also conducted a survey on disability in Quarter 2, 2002 as a module of its Quarterly National Household Survey (QNHS) which concentrates on employment activity. The QNHS in 2002 recorded 10.3% of all people aged 15-

64 reporting a disability/health problem (CSO, 2004b). This module was repeated in Quarter 1 in 2004 with very little change in the numbers reporting a disability, 10.9% of all people surveyed, numbering 298,300 in all, with just under half of those (142,500) being women. Only 37% of this 298,300 were in employment compared with 63.8% for the total population (CSO, 2004b). These figures have implications for the poverty and continuing social exclusion faced by people living with a disability, the vast majority of whom do not have an earned income because access to the labour market is so poorly supported (Conroy, 2003:pg. 48). The CSO intends to repeat the QNHS at intervals, which will build up longitudinal data on employment patterns that will constitute one measure of the effectiveness, or otherwise, of social inclusion policies.

2.3.3. Development of expanded Census categories exploring disability

This initial CSO QNHS data provided useful interim figures on the extent of disability in Ireland, while the National Disability Authority piloted an in-depth data collection exercise for a post-Census survey of those registering themselves on the Census returns as having a disability (Doyle, 2003:pg. 11-12). This work complemented that of the Statistics Board, carried out in conjunction with the Department of An Taoiseach, to develop data collection tools to cover anyone affected by any of the 9 grounds for discrimination identified in the Employment Equality Act, 1998 and the Equal Status Act, 2000 (Doyle, 2003:pg. 12).

The work of framing more sensitised questions, which included consultation with service users and interested Non-Governmental Organisations (NGOs), resulted in the 2006 Census using an expanded number of categories to explore disability in questions 15 and 16 of the Census form (CSO, 2007a). The categories were as follows:

-Blindness, deafness or a severe vision or hearing impairment
-A condition that substantially limits one or more basic physical activities

-Difficulty in learning, remembering or concentrating
-Difficulty in dressing, bathing or getting around inside the home
-Difficulty in going outside the home alone
-Difficulty in working or attending school/college
-Learning or intellectual disability
-Psychological or emotional condition
-Difficulty in participating in other activities
-Other, including chronic illness
(CSO, 2007b).

With modifications to the questions used, the 2006 Census yielded a figure of 9.3% of the population having a disability, and a higher number reporting more than 1 disability, 62%, compared with the 58.1% figure from 2002 (CSO, 2007b). The breakdown of figures on women with a disability between the ages of 15 and 44 (almost the entire span of reproductive years in a woman's life) revealed a total population of 52,232 (CSO, 2007b:pg. 45).

2.3.4. The National Disability Survey

2.3.4.1. Women of child-bearing age

Figures from the National Disability Survey (NDS) are subject to sampling error, particularly where small subsamples are involved, so should be taken as indicating a 'ballpark' or broad order of magnitude rather than precise figures. These figures show about 20,000 women aged 18-34 and about 18,500 women aged 35-44 had a disability in one or more of the 9 categories used in the survey (National Disability Survey, vol. 1 Table 5B). The most frequently-cited conditions for women of childbearing age were mental health conditions, pain, mobility, intellectual and learning disability, and difficulties in remembering and concentrating (Table 1).

Table 1 - Number of women of childbearing age with different kinds of impairment (Thousands)[2]

	18-34	35-44	Total 18-44	% of disability among total number of women in this age group
Seeing	1.9	1.3	3.2	0.4%
Hearing	1.7	1.8	3.5	0.4%
Speech	2.6	1.2	3.8	0.4%
Mobility & Dexterity	7.1	8.6	15.7	1.8%
Remembering & Concentration	6.7	5.3	12.0	1.3%
Intellectual & Learning	6.9	3.2	10.1	1.1%
Emotional, psychological & mental health	8.8	10.0	18.8	2.1%
Pain	7.8	9.6	17.4	2.0%
Breathing	3.0	2.9	5.9	0.7%
Total Disabilities	46.6	44.0	90.6	
Persons with a disability	20.0	18.5	38.5	4.3%
Average disabilities per person	2.3	2.4		

Source: National Disability Survey Vol. 1 Table 6b
These figures are subject to sampling error and represent broad orders of magnitude only

2.3.4.2. Sight impairment

According to the National Disability Survey, the number of women of childbearing age with significant sight impairments is of the order of 3,200. Overall, just over half of people with sight impairments recorded in the NDS reported a moderate level of impairment, about 40% reported a lot of difficulty and about 5% could not see at all. If women with sight impairments and of childbearing age were proportionately represented in the 2007 births, there would have been of the order of 280 births to such women.

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[2] These categories are not mutually exclusive.

Comhairle (now Citizens Information Board) in conjunction with the National Council for the Blind of Ireland contacted all registered blind people in 2004 to ascertain their preferred form of communication with public bodies. The results of this exercise, in which 1,800 people participated, showed that 54% preferred to use large print, 35% would like audio communication and 3% preferred to use Braille.

2.3.4.3. Hearing impairment

About 3,500 women of childbearing age have significant hearing impairments. If women with hearing impairments were proportionately represented in the total number of births in 2007, there would have been of the order of 280 births to such women. Of these, the number who would be expected to have a lot of difficulty in hearing, or total absence of hearing, would be approximately 95. This is given that, overall, about 60% of people of all ages with hearing impairments have a moderate level of difficulty, about a third have a lot of difficulty, and about 3% cannot hear at all.

In general, people with hearing impairments report finding it somewhat easier to communicate with health professionals than with others providing everyday services; however, this may reflect a relationship with a particular health professional and may not apply in respect of short hospital stays for maternity care. Overall, about one in ten people with a hearing disability reported they were unable to communicate with a health professional, while twice as many reported they could not communicate with others providing everyday services. About 45% reported some difficulty communicating with people providing everyday services, but 37% had moderate difficulty communicating with health care professionals. About a third had no difficulty communicating with people providing everyday services, and this rose to half in the case of health professionals (ibid, Table 15.7).

2.3.4.4. Speech disabilities

The number of women of childbearing age with speech disability is of the order of 3,800. While there is some overlap between hearing and speech disabilities, there are a number of other conditions that can lead to speech difficulties. In general, this group report greater degree of difficulty in communicating with health care professionals and other service providers than do persons with a hearing disability. Half report that they are unable to communicate with service providers generally, while about a third report that they cannot communicate with health service staff. About 40% can communicate with health service staff with difficulty, falling to about 35% in respect of other service providers. About a quarter have no difficulty communicating with health service professionals, but only half that number have no difficulty communicating with other service providers (ibid, Table 16.7).

2.3.4.5. Mobility and dexterity impairments

About 16,000 women of childbearing age, or about 2% of women in this age group, have disabilities affecting their mobility or dexterity. Most of these report that they have difficulty walking for 15 minutes, while about a third have difficulty using hands or fingers. Across all age groups, about one in six people with impaired mobility uses a wheelchair.

2.3.4.6. Mental health difficulties

A national database on mental health does not exist in Ireland although there are statistics on aspects such as in-hospital bed occupancy rates available through the National Psychiatric Reporting System (Doyle, 2003); however, this information is extraordinarily limited in scope. Whereas it might outline how many women have been admitted, little else can be gleaned from available socio-demographic data. The HRB is, however, developing the WISDOM database (formally known as COMCAR/NPIRS), which will cover all components of the mental health services, including individual’s usage of community and inpatient services, as part of the Mental Health Research Programme 2007-2011 (HRB, 2006, 2008).

Some data are available, however, from the National Psychological Well-being and Distress Survey (NPWDS), carried out by the Mental Health Research Unit (MHRU) of the Health Research Board (HRB) in 2006 (Tedstone Doherty et al, 2007). Out of 2,711 respondents, 18.5% (n=490) of females had dependent children younger than 18 years old living in their household, and of those, the majority (86.1%, n= 420,) rated their mental health in the last 12 months as good or very good, 10.7% as fair (n=52), and 3.1% (n=15) as poor or very poor. Seventy-eight (15.9%) of the 490 females living with children younger than 18 years old reported that they had experienced a mental, nervous or emotional problem in the last 12 months, and 11% (n=54) had spoken with their General Practitioner (GP) at least once in the past 12 months about being anxious or depressed. Slightly over 6% of females living with children under 18 (n=30, 6.3%) reported use of mental health services or professionals (such as in-patient units, day centre psychiatrists or nurses) at least once within the past 12 months (Tedstone Doherty et al, 2007), which gives an approximate picture of the services that might be required.

About 19,000 women of childbearing age, around 2% of the age group, report emotional, psychological or mental health difficulties. Across all age groups, depression is the most common mental health condition, followed by anxiety (National Disability Survey, vol 1 Table 20.6). Almost 90% of women with mental health difficulties in this age group report that they have a lot of difficulty or cannot do everyday activities.

2.3.4.6. Intellectual or learning disability

Since 1995, the National Intellectual Disability Database has compiled figures on the numbers of people with intellectual disabilities based on those who are in receipt of services or on the waiting list for intellectual disability services. The database is updated annually, and currently covers more than 25,000 people. People with mild intellectual disabilities, who are neither in receipt of intellectual disability services nor are deemed to require such services in the next 5 years, are not included in the database.

The published data distinguishes those aged 15 to 34, and those aged 35-54. The incidence of intellectual disability for women is calculated at 8 per 1,000 for women aged 15 to 19, 5.4 per 1,000 for women aged 20-34 and 6.1 per 1,000 for women aged 35 to 54. In 2007 there were around 4,000 women aged 15-34 with an intellectual disability recorded on the database. Of these, 40% were categorised as having a mild disability and 40% as having a moderate disability (NIDD 2007, Table 2.2)

The data from the National Disability Survey shows around 8,200 women aged 18-44 diagnosed with an intellectual disability (Table 6B), and around 10,100 women in this age group in the broader category of "intellectual or learning disability" which would include also such specific learning disabilities as dyslexia and Attention Deficit Disorder.

2.3.4.7. Conclusion

This section has documented available information from official sources on the number of women with disabilities of childbearing age, and the incidence of such disability in this population. Where the information is based on small sub-samples, it indicates a broad order of magnitude only. While the number of women with disabilities who require pregnancy and maternity services is likely to fluctuate from year to year, this information may be of value to service planners in giving a broad indication of how many women with disabilities may present for maternity services in any year.

2.4. Limits of published research

The comprehensive review of national and international literature revealed how research examining the health services experience of women with disabilities (physical, sensory, intellectual and mental) during pregnancy, childbirth and early motherhood is relatively unexplored (Grue and Tafjord-Laerum, 2002; Lee and Oh, 2005). From an Irish perspective, research in the areas of sexuality, reproductive freedoms and motherhood for women with disabilities is limited (Doyle et al, 1985; Kennedy, 2004; Steinberg, 2006). From an intellectual disability perspective, in particular, the literature search yielded little information on the topic in hand but did provide an insight into the context within which pregnancy and parenthood within the intellectual disability population is viewed.

A large volume of literature focused on controversial issues including the coerced planned termination of pregnancy and the constant questioning of the 'right to parent', especially in relation to persons with a mental health difficulty or intellectual disabilities. The following sections provide a background and context in relation to society's attitudes to, and disabled women's experiences of, pregnancy, childbirth and motherhood in Ireland.

2.5. Physical and sensory disability: pregnancy, childbirth, and early motherhood

2.5.1. Background and context

Women and girls are the largest group in the global disability population, and, historically, have been subjected to multiple types of discrimination (Tilley, 1998). In comparison to men with disability, women with disability are less likely to marry, have a higher incidence of divorce, earn less money, and are viewed more negatively by themselves and others (Tilley, 1998). They are thus considered by many to be among one of the most disadvantaged groups in modern society (Thierry, 1998).

Women with physical disabilities express a strong perception that they themselves, and their lives, are invisible to others (Pierce, 2003; Zitzelsberger, 2005), particularly when interacting with health care professionals, who appear to view women as powerless and passive users of services (Grue and Tafjord-Laerum, 2002). Combined with inadequate information provision, poor communication, and no opportunity to influence decision-making, women are disempowered and, consequently, negative feelings such as fear, anger, disappointment, distress, guilt, and inadequacy take hold (Baker et al, 2005).

The fundamental right to health and attainable quality health care is an important provision for women with disabilities but it also serves as a means for women to live independently and to fulfil a life of active participation and inclusion in modern society. Moreover, access to quality health care and best practice is essential for women with physical disabilities because they face unpredictability in relation to the impact pregnancy may have on their disability and, similarly, the impact physical disability will have on their pregnancy (Conine et al, 1986; Smeltzer, 1994; Baker et al, 1997), and on their abilities to adapt and cope effectively with the transition to parenthood.

2.5.2. Evolution of the concept of disability

Disability is a highly complex concept with varying definitions. In more recent years, the traditional concentration on the functional deficits and problems of the individual, where the term ‘disability’ implies incapacities or failings on behalf of the person, or a defect or impairment of themselves (Michailakis, 2003) has been robustly challenged (Verbrugge and Jette, 1994). The social model of disability determines that pathology is not intrinsic to the individual (Gronvik, 2007), but rather disability is perceived to be a functional limitation(s), resulting primarily from environmental and social barriers, inadequate access to essential rehabilitation therapies and assistive technologies.

In 1976, the World Health Assembly of the World Health Organization approved for publication a classificatory instrument for disability, the International Classification of Impairments, Disabilities and Handicaps (ICIDH). In this instrument, the term ‘impairment’ was used to describe the functions and systems of the body affected (e.g. cardiac, respiratory), ‘disability’ was used to describe limitations in, for example, a person’s mobility, or ability to perform personal care, and ‘handicap’ was used to describe the disadvantages experienced by people in their environment (for example, in employment or independence). Facets of both the medical and social models are apparent, but the model does not clearly acknowledge that the presence of barriers and the absence of facilitators contribute in any way to the difficulties that a person with a disability experiences. The social model of disability is thus only partially adopted and is never clearly acknowledged or operationalised.

In 1993, the World Health Organization began revising the ICIDH, seeking the assistance of disability groups from around the world, including Disabled Peoples International, along with professional groups such as the American Psychological Association and the American Occupational Therapy Association. Two drafts were produced and critiqued and in 2001 the final version, called the International Classification of Functioning, Disability and Health (ICF) was published. This classified functioning at both the level of body/body part, whole person, and whole person within a social context, thus incorporating holism or universalism as its guiding principle (Bickenbach et al, 1999). The main change was that the instrument acknowledged that the environment has an interactional effect on people, which may assist or hinder their participation in life activities, and that this may be more instrumental in a person's inability to participate than the limitations associated strictly with their physical, mental, or emotional state (Lollar and Crews, 2003).

2.5.3. Society's attitudes to women with disability

According to Tilley (1998), many of the challenges encountered by women with disabilities when accessing health care are located in prejudicial social attitudes and discriminatory and exclusionary practices of individuals, organisations and institutions. In particular, 'The attitudes of medical professionals towards disabled women as child bearers have often been based on myth rather than fact' (Kallianes and Rubenfeld, 1997: pg 208). These women may experience multiple layers of discrimination, exclusion and inequalities in access to, and use of, mainstream healthcare services (Combat Poverty Agency, 1995). All women experience challenges when accessing health care, but for women with disabilities the challenges are often disproportionate and inequitable (Lawthers et al, 2003). Health inequities are said to be those differences that are unnecessary, avoidable, unfair and unjust (Whitehead, 1992). Such inequities evolve from a complexity of factors including the segregation of women with disabilities, attitudinal barriers, physical barriers and the unmet needs for advocacy (Pillinger, 2004). No single challenge can be considered as compromising a women's access to health care, rather the challenges are an accumulation of several factors (Scheer et al, 2003). These challenges prevent women from accessing health care when required and only serve to isolate and alienate women with disabilities (Grabois et al, 1999) and lead to them feeling as though they have failed as wives and mothers (Mitton et al, 2007). While these challenges may be relatively insignificant for women without a disability, for women with disabilities who need more interaction with, and have an increased need for, appropriate and accessible health care services, the challenges are very significant (Parish and Huh, 2006) and equate to an additional disadvantage in women's health and well being (Iezzoni, 2003).

2.5.4. Reproductive control

Many authors have argued that for women with physical disabilities the politics of eugenics has had a long-standing influence on repression of reproduction and the parenting role (Finger, 1992; Waxman, 1993; Kallianes and Rubenfeld, 1997). In addition, health care professionals and broader society exerted paternalistic control (Waxman, 1993; Kallianes and Rubenfeld, 1997; Bau, 1999) over such women's reproductive and mothering rights, consequently many disabled women's identities were unseen and unquestioned (Zitzelsberger, 2005).

Often, women with physical disabilities are presumed to be unable to cope with pregnancy, birth and motherhood and are counselled not to become pregnant (Tilley, 1998; NDA, 2007). Tait (1986) notes how women with disabilities are generally economically less privileged and socially more defenceless, and how these women continue to be deprived of the ability to reproduce by forced sterilisation, often by means of a hysterectomy. Data on the frequency of sterilisation among women with a disability are sparse. A large-scale study undertaken by Nosek et al (2001) compared the reproductive health of women with a physical disability (n=476) and non-disabled women (n=406) in the United States. It identified that 22% of disabled women had undergone a hysterectomy compared with 12% of non-disabled women (Nosek et al, 2001). Numerous authors argue that women with disabilities experience a double vulnerability, because of their gender and disability (Tilley, 1998; Lloyd, 2001; Lee and Oh, 2005; Zitzelsberger, 2005; Gavin et al, 2006) resulting in their isolation and marginalisation.

The literature also indicates a concerning trend among attitudes and behaviour of professionals. Women reported being advised and/or offered (unsolicited) immediate termination of pregnancy at the time of diagnosis of their pregnancy (Piotrowski and Snell, 2007). Many women reported being offered additional prenatal anomaly screening (Stern at al, 2002; Piotrowski and Snell, 2007) and, more worryingly, reported feeling pressurised to consent to such genetic screening. This advice, even if portrayed in a benevolent manner, aimed to reduce the risk of inherited disability to the fetus (D'Eath et al, 2005) and frequently left women feeling guilty or selfish if they gave birth to a disabled child (Gillespie-Sells et al, 1998).

2.5.5. The effect of physical disabilities on pregnancy

Women with some physical disabilities have a higher incidence of complications during pregnancy and birth (Cross et al, 1992; Nunn, 1996; Baker et al, 1997; Nosek et al, 2001; Gavin et al, 2006), thus they are categorised as 'high-risk' and their options for different provisions of care are limited. For example, of 231 women with spinal cord injury aged between 18-45 years, only 50% of those who became pregnant had a vaginal delivery, and many had postpartum complications (Charlifue et al, 1992). In contrast, women with multiple sclerosis (MS) do not appear to experience adverse outcomes in pregnancy (Houtchens, 2007). Despite this, women with MS have many fears and concerns when planning to become pregnant (Smeltzer, 2002), and may need assistance with making their decision (Prunty et al, 2008a).

Some women with disabilities have found maternity care to be disjointed, reactive and delivered in an untimely manner (Albrecht, 2001) and others did not receive gynaecological screening services when necessary (Coyle and Santiago, 2002). Many expressed concerns about genetic inheritance of disability, while others struggled with the decision to forego essential medication for their medical condition to ensure a healthy baby (Baker et al, 1997; Carty, 1998). For women post spinal cord injury, sexual desire remains relatively unchanged when compared to pre-injury desire (Demasio and Magiples, 1999), and becoming pregnant after spinal cord injury is an achievable objective and should not be discouraged (Ehrenberg et al, 2003). In fact, many studies of women with physical disabilities (Greenspoon, 1986; Wanner et al, 1987; Charlifue et al, 1992; Cross et al, 1992; Baker and Cardenas, 1996; Nunn, 1996; Baker et al, 1997) have identified that pregnancy can be relatively straightforward, and medical evidence suggests that spontaneous vaginal delivery should be the preferred mode of delivery provided the pregnancy remains obstetrically uncomplicated (Sasa et al, 1998).

Pregnancy and delivery will, however, require careful monitoring for potential medical complications (Demasio and Magiples, 1999). The most frequently reported complications for which monitoring is necessary include autonomic hyper-reflexia (AH), anaemia, respiratory compromise, urinary tract infection, thromboembolic disorders, and skin breakdown/pressure sores (Greenspoon, 1986; Wanner et al, 1987; Charlifue et al, 1992; Cross et al, 1992; Baker and Cardenas, 1996; Nunn, 1996; Welner, 1997; Sasa et al, 1998; Demasio and Magiples, 1999; Jackson and Wadley, 1999; Ehrenberg et al, 2003; Thierry, 2006; Jackson and Mott, 2007). Preconception counselling is critical for this cohort of women and should address the obstetrical, psychological and social impact of pregnancy (Demasio and Magiples, 1999; Thierry, 2006).

2.6. Mental health and illness: pregnancy, childbirth, and early motherhood

2.6.1. Historical perspective

2.6.1.1. Introduction

Kallianes and Rubenfeld (1997) express the view that society and the medical establishment have exerted paternalistic control over both disabled and non-disabled women's bodies and reproductive capacities and rights. In the context of women with mental health difficulties, such control was further exacerbated by, firstly, the eugenics beliefs that mental illness had a strong genetic component, and that procreation among people with mental health difficulties would lead to social degeneracy and 'race suicide' (Shorter, 1997; Whitaker, 2002). Secondly, women with mental health difficulties were portrayed as hypersexual, predatory and 'temptresses' (Showalter, 1985). Consequently, individuals who experienced mental health difficulties were controlled through institutionalisation, with staff being instructed to maintain gender segregation, and guard against any 'illicit' associations between men and women (Showalter, 1985; Apfel and Handel, 1993; Busfield, 1996). Although celibacy was the official rule to be observed, Chesler (2005) noted that women in institutions were often sexual victims and not protected from 'rape, prostitution, pregnancy, and the blame for all three' (Chesler, 2005:pg. 98).

2.6.1.2. Reproductive control

Prohibition of marriages for certain groups of people, including 'lunatics' and 'imbeciles' was introduced in the United States of America (U.S.A.) and many European countries during the early 1900s (Krumm and Becker, 2006). Taken to the extreme, eugenic arguments were made for the complete removal of ovaries and testes (Barr, 1912), and in some countries, degeneracy theory gave rise to such radical measures as laws that authorised sterilisation without informed consent. Shorter (1997) suggested that it was only after the atrocities of World War II that degeneracy theory and reference to eugenics became a social and professional taboo. In today's context some people suggest that the drug-induced suppression of sexual desire and the production of hyperprolactinaemia in women, with its impact on fertility, is another more subtle way of maintaining existing power relations and enforcing reproductive control, under the guise of therapy (Vandereycken, 1993; Deegan, 1999). Indeed, Vandereycken (1993) suggests that the image of people having no control over their sexual drives, especially women who experience psychosis, is a factor that influences support for the use of drugs to suppress sexual desire.

2.6.1.3. Separation of mothers from children

Howard (2000) examined, from a historical perspective, the separation of mothers with mental illness from their children. He noted that psychiatric textbooks, written in the first half of the century, predominantly by male psychiatrists, advocated the complete and prompt separation of ill mothers from their children, with little or no reference to the impact of such separation on either mother or child. Grunebaum et al (1975) attribute this practice to a number of beliefs dominant in psychiatric thinking at the time: the belief arising out of psychoanalytic theory that the mother's illness was partly due to her hostility towards her child, a belief that the mother was potentially dangerous with homicidal or suicidal tendencies, and a concern that the presence of a young child on a psychiatric ward would upset the management of the ward. The notion of the 'schizophrenogenic mother', put forward by Fromm-Reichmann as a cause of schizophrenia, gave further support to the belief that mothers who experienced mental health difficulties were dangerous and should be separated (Howard, 2000).

In the culture that stigmatised single mothers and even more so mothers with mental illness, many mothers with mental illness were forced in an atmosphere of secrecy and shame to give up their children. Often, it was considered kinder and easier if the mother never saw the child they were giving up for adoption. Therefore, not infrequently, these mothers gave birth under general anaesthetic and had their babies taken away immediately. In addition, documentation about the pregnancy and birth was poor or non-existent, making it impossible for children to reconnect with their birth mother (Schen, 2005). Apfel and Handel (1993) found in the era of secret adoptions, many of the mothers who were in mental hospitals had no opportunity to mourn the loss of their children, and consequently suffered unresolved grief and profound depression. Some of these mothers experienced exacerbation of their psychotic symptoms at the time of the child's birthday, which frequently went unnoticed by staff as they were unaware of the significance of the date or, indeed, of the woman's status as a mother.

2.6.1.4. Lack of acknowledgement of sexuality

Many theorists have argued that once women were confined to an institution they were generally considered by society to be genderless, asexual beings, with a presumed incapacity or desire to pursue adult roles, such as establish further intimate relationships, have children and mother (Showalter, 1985; Apfel and Handel, 1993; Busfield, 1996). Apfel and Handel (1993) suggest that health care professionals came to view sexuality and reproductive issues as 'troublesome intrusions of the normal into the decidedly abnormal world of the patient' (pg. 2). The portrayal of women with mental health difficulties as asexual, lacking any desire to have children is evident, even today, in the number of mental health services who routinely fail to collect data on whether women attending their service have children (Nicholson et al, 1993; Dipple et al, 2002), or discuss either contraception or the impact of prescribed medication on fertility and sexual function with these women (Dorsay and Forchuk, 1994; Cole, 2000; Higgins, 2007).

2.6.2. Mental health difficulties and pregnancy

2.6.2.1. Introduction

For most women, pregnancy and motherhood is a positive psychological process. However, for some women this life changing event can result is a mental health difficulty. It was previously thought that pregnancy somehow insulated and protected women from the pressures of the outside world and their own internal processes. Even if a mental health difficulty had been previously diagnosed, it was believed that it went into ‘remission’ during pregnancy (Solchany, 2003). We know now that this is untrue and pregnant women are vulnerable to developing, at the same rate, the same range of mental health difficulties such as general anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder, depression, substance abuse and psychosis, as any other women (Kelly et al, 2001). In addition, there is an increased risk that previous psychotic illnesses such as schizophrenia or bipolar illness can re-emerge during pregnancy, childbirth and the postnatal period. The converse is also true, with some evidence that adverse obstetric events leads to presentation of schizophrenia in the mother at an earlier age (Kelly et al, 2004).

2.6.2.2. Postnatal depression

It is estimated that at least half of the women who give birth, at some point in the pregnancy or in the initial weeks following the birth, will experience changes in their emotions and mood. These changes, a normal part of adjusting to changed circumstances and often subsiding with rest, support and reassurance, should not be pathologised and confused with a mental illness. However, O’Hara and Swain (1996) found that 25% of women who experience what is often referred to as the ‘baby or maternity blues’ went on to experience depression. It is estimated that between 15%-20% of women will experience some form of depression in the first 12 months postnatally, with an increased risk of life-time depression (Bernazzani and Bifulco, 2003). Lower figures of between 8 and 12% have been found for women within the first 9 weeks of delivery if depression is assessed according to the more stringent clinical diagnostic criteria of the Diagnostic and Statistical Manual (DSM) or the International Classification of Diseases (ICD) (O'Hara and Swain, 1996). Some studies have shown that women who have emergency delivery are between 2 and 6 times more likely to develop postnatal depression (Boyce and Todd, 1992; Koo et al, 2003) although other work disagrees (Patel et al, 2005).

For up to 50% of women who experience life-time depression, postnatal depression was the index episode (Stowe and Nemeroff, 1995). Oates (2007) finds that 10% of new mothers are likely to develop depression in the year following childbirth, of whom between one third and a half will suffer from a severe depressive illness. However, only 0.4% of women who experience a postnatal illness require admission to a psychiatric unit (Edwards and Timmons, 2005). Beck (1998) emphasises the importance of differentiating between postnatal depression and postnatal anxiety and panic disorders. Otherwise, women who have postnatal onset of anxiety or panic disorders may be misdiagnosed and treated for depression. Although research has placed great emphasis on depression in the postnatal period, it is estimated that 15% of women will also experience depression during pregnancy. Brockington (2004) suggests that the widespread use of this term ‘postnatal depression’ in connection with childbirth may be a means of reducing the stigma associated with serious mental illness. Others are of the view that the tendency is reflective of the biomedical focus of both maternity and mental health services, which neglects the multiplicity of psychosocial problems experienced by women during pregnancy and early motherhood (WHO, 2000; Austin and Priest, 2004).

2.6.2.3. Postnatal psychosis

Psychosis in the early postnatal period - often termed postnatal or puerperal psychosis and much rarer than postnatal depression - affects between 1 to 2 women per 1,000 births (National Institute of Clinical Excellence (NICE), 2007). Some suggest that the term puerperal psychosis should be confined to psychosis beginning within 2 weeks following delivery, to distinguish it from other psychotic disorders naturally occurring in the general population (Coyle, 2003). Postnatal psychosis is considered an emergency and requires an immediate intervention, which usually includes hospitalisation. In a long term study of puerperal psychoses from 1927-1961, Protheroe (1969) found that only 1 of the 114 women he traced had stayed in hospital since being admitted in 1941. In relation to the remainder, 49 women had at least 1 further psychotic episode, 14 of which were related to childbirth. During the follow up period 61 women were known to have 149 further pregnancies. All except 6 of the 104 women traced following discharge were living, or lived until they died, in satisfactory relationships and in reasonably well-kept homes and thus appeared to have had a satisfactory outcome. However, the author traced the long term outcomes of these women using case notes only, which might not have fully documented the psychosocial aspects of these women's lives. The author also examined the family histories of 98 of the women from which no specific genetic predisposition to puerperal psychosis could be identified.

2.6.2.4. Risk to mothers with mental health difficulties

Mental health difficulties during and after pregnancy have implications for the psychological and physical welfare of the woman, fetus/baby and the family. Until recently it was thought that pregnancy exerted a so called 'protective effect' on women's risk to maternal suicide. However, the Confidential Enquiry into Maternal and Child Health (CEMACH) found that mental health difficulties (suicide, or 'accidental' but lethal overdose of drug of abuse) contributed to 12% of maternal deaths in the United Kingdom, with more women dying from the direct and indirect consequences of substance abuse than from other psychiatric causes (Lewis, 2007). The majority of suicides in pregnant and postnatal women occur in the 6 weeks before delivery and the 12 weeks after delivery. As with previous reports, the majority of women who died from suicide were receiving some type of psychiatric care, but not specialist drug addiction services. The report also revealed that many of the deaths took place shortly after a child protection conference, or a child being removed into care.

2.6.2.5. Risk to the fetuses/neonates of mothers with mental health difficulties

Although all pregnancies carry risk, especially to the fetus, research suggests that these risks increase where the woman has a mental health difficulty. According to the National Institute of Clinical Excellence severe depression is associated with increased rate of still birth, postnatal specialist care for the baby and low birth weight babies. Maternal psychosis and bipolar disorder appear to increase the risk of infant mortality and stillbirth, and have also been associated with preterm delivery and low-birth weight infants (NICE, 2007). Women who experience eating disorders during pregnancy are more likely to have complications, such as miscarriage, delivery by caesarean section and premature or small babies.

2.6.2.6. Risk to the children of mothers with mental health difficulties

There is now emerging evidence that untreated mental health difficulties in pregnancy may be associated with poorer long term outcomes for children beyond the immediate postnatal period. Studies have shown that untreated or enduring mental health difficulties in the mother may impact negatively on the emotional and cognitive development of the child. A number of studies suggest that children of postnatal depressed mothers are more likely to have difficulties in relationships and attachments. Mothers with a diagnosis of depression are considered to interact less with their infants, and to be less affectively and interactionally synchronised with their children (Cox et al, 1987; Fendrich et al, 1990; Goodman and Brumley, 1990; Hammen et al, 1990; Kelly et al, 1999; Mullick et al, 2001). While not discounting Mullick et al's view (Mullick et al, 2001) that a small number of severely ill women with psychotic symptoms may experience thoughts leading them to harm their children, the tendency within the research to emphasise the cost of the mother’s pathology on the development of the child has resulted in motherhood and mental illness becoming synonymous with negative parenting regardless of diagnosis, severity of experiences, support systems and family circumstances and social context (Cogan, 1998; Mowbray et al, 2000). In addition, it is clear that many children are resilient and appear to avoid significant problems, yet very little research has focused on identifying sources of resilience or on what makes for positive outcomes.

2.6.3. Motherhood and mental distress in context: social and personal circumstances

2.6.3.1. Social circumstances

The medical model, which has dominated women's experiences of childbirth, has been criticised for pathologising postnatal events and ignoring the social context of many women's lives. Perinatal mental illness is a complex issue, and the social context in which women live and parent plays an important role in its cause, as well as exacerbating existing mental health difficulties and the everyday challenges of parenting. Separation, divorce, lone parenting, relationship difficulties, poor social support, and stressful life events during pregnancy have all been identified as factors contributing to or exacerbating pre- and postnatal mental health difficulties (Whiffen and Gotlib, 1993; O'Hara and Swain, 1996; Borjesson, 2005; Horwitz et al, 2007). The strongest predictors of postpartum mental illness, especially depression, are past history of illness (Verkerk et al, 2005; Kim et al, 2008), low social supports, stressful life events during pregnancy, high levels of birth complications, traumatic births, and relationship difficulties (O'Hara and Swain, 1996). Evidence suggests that low family income, lower occupational status and financial strain are also associated with increased risk (O'Hara and Swain, 1996; Horwitz et al, 2007).

Many of these factors are present in the lives of mothers with enduring mental health difficulties. These issues add to the stresses of parenting and can adversely affect and thwart women's wishes to parent well. Research both in Australia and the U.S.A. reveals much about the difficulties and complexities of women's lives as they cope with the dual demands of motherhood and living with a mental health difficulty. A great number of women enduring mental health difficulties have begun child bearing early, are low income parents, with high rates of unemployment (Nicholson et al, 1998c; Mowbray et al, 2000; Mowbray et al, 2001), are parenting alone, have smaller social networks and live in suboptimal accommodation (Caton et al, 1999; Chernomas et al, 2000; Oyserman et al, 2000). Marital discord, social isolation and conflicts with extended family are also common within this group of women (Oyserman et al, 2000). Congruent with this picture, is a high number of women who reported difficulties paying off debts as well as paying for basic necessities such as food and clothing, which further exacerbated their poor self-esteem and feelings that they were bad mothers (Mowbray et al, 2000).

2.6.3.2. Personal circumstances

Research also suggests that women with mental health difficulties experience a significant number of unplanned pregnancies, as a result of failed contraception or lack of use of contraception (Miller and Finnerty, 1996; Barkla et al, 2000). In Barkla et al's (2000) Australian study, 52% (134) of the women with enduring mental health difficulties experienced 'unplanned 'pregnancies, with 25% of these ending in termination. Although these figures may reflect the trend of unplanned and terminated pregnancy in the general population, and the degree of 'wantedness' can change over time, women who have terminations in difficult psychosocial contexts are at high risk of depression. Women with an enduring mental illness are also at a greater risk of being deprived of their parenting role through miscarriage, stillbirth and custody loss (Dipple et al, 2002). Studies have reported that 20-30% of women with prenatal loss of a child (stillbirth or neonatal death) have appreciable depressive symptoms up to 30 months after the loss, with rates of clinical depression in women after a miscarriage ranging from 40-50% (Bernazzani and Bifulco, 2003).

Many mothers with mental illness have experienced adversity and trauma in childhood, such as physical and sexual violence. Experiences such as childhood sexual abuse are associated with depression in adulthood. In addition, the obstruction of attachment in childhood impacts on the ability to form stable relationships in adulthood, and can result in the development of a personality disorder (Miller and Finnerty, 1996; Brunette and Dean, 2002; Bosanac et al, 2003; Dickerson et al, 2004). It is important, therefore, that mental health professionals identify which women clients are parents, so that appropriate, focused parenting services and supports are offered.

While mental health services are now addressing needs for housing, work and education among people with enduring mental health difficulties (Government of Ireland, 2006), they are far behind in responding to the needs of women as mothers (Mowbray et al, 1998; O'Shea et al, 2004). It is evident from the literature that many women routinely seen by the mental health services are not identified as parents and the parent role function is ignored in care and treatment planning (Zemencuk et al, 1995). Nicholson et al (1993) found that few American Mental Health Services routinely collected data on whether women attending services had children and most neglected to ask about family roles and responsibilities. Dipple et al’s (2002) study in the United Kingdom also highlighted the inadequacy of women’s case notes, regarding their role as mother. This included records with no mention of children, the incorrect number of children, inadequate information to enable mother or staff to contact children easily, and incidents where a major event such as the death of a child was not recorded. This is indicative of the tendency of services to neglect the community and family context of women’s lives and the specific psychosocial needs of mothers. It is also indicative of the biomedical paradigm and its focus on the woman as ‘patient’ as opposed to mother with, consequently, the identity of the woman as ‘mentally ill’ becoming primary, supplanting all other identities (Oyserman et al, 2000; Montgomery et al, 2006).

2.6.4. Positive aspects of mothering for women with mental health difficulties

The literature on motherhood and mental illness is largely dominated by a professional discourse that portrays mothers with enduring mental health difficulties as ‘risky,’ incompetent mothers. However, there is a small emerging body of literature that gives voice to these women and recognises that they are capable of effective parenting with support from innovative services and resources. Mothers with severe mental health problems say that motherhood helps provide them with an identity, other than that of being ‘mentally ill’ (Chernomas et al, 2000; Oyserman et al, 2004; Montgomery et al, 2006), and report that looking after children is rewarding and central to their lives, even though the demands of parenting are considerable (Schwab and Clark, 1991; Mowbray et al, 1995a). Krumm and Becker (2006) point out that frequently women with enduring mental health difficulties, due to educational background, have fewer occupational options in comparison to women without a diagnosis of mental illness. They suggest that this may contribute to these women's desire to have a normal reproductive biography, as motherhood is seen as an expression on 'normality' and a chance to be competent in a valued social role.

Motherhood for some women is an opportunity to be fulfilled and creative- a means of feeling love, delight, warmth and normality. In a study of 24 mothers with mental health difficulties, Mowbray et al (1995b) reported that, for 81% of the women, transition to motherhood was a positive experience and they felt very positive about their children and parenting skills. The mothers described parenthood as a way of promoting personal growth and development and a key outlet for expression of feelings of care and concern. The majority of women (n=22) in Diaz-Caneja and Johnson's (2004) qualitative study said that having children gave them a purpose in life, made them feel fulfilled as women and increased their self-esteem. The significance of having children is also illustrated by women's experiences of parenting as 'the only time they felt like an adult' (Schwab and Clark, 1991:pg. 97). For parents who did not have custody of their children, but had visiting rights, seeing their children was an important focus in their lives (Schwab and Clark, 1991; Joseph et al, 1999).

Motherhood also signified responsibility, with some women expressing concerns about the impact of the illness on their children, and worrying about the children becoming ill, whether from genetic or environmental reasons (Mowbray et al, 1995a; Diaz-Canjela and Johnson, 2004). Being responsible meant protecting and shielding the children from the illness through pretence, downplaying, and camouflage of emotions and distress. By hiding the 'illness' and related distress the mothers believed that they could be viewed as 'normal'.

Therefore, their parenting would not be questioned and they would be affirmed by their children and others (Montgomery et al, 2006).

Babies and children also provide a social and community context for mothers, as rearing a child connects the mother with other mothers, schools, playgroups and paediatric health professionals For some women, becoming a mother meant moving from the position of 'stigmatized outcast' to a valued and honoured member of society (Apfel and Handel, 1993). For other women the wish to bear children is enormous, even in the face of previous losses of children or consequence to one's own mental and physical health (Apfel and Handel, 1993). Having children was viewed by mothers as having many beneficial effects on their mental health. Motherhood was seen as a motivating factor to sustain their participation in treatment or engage with psychiatric services in the community in order to prevent relapse (Mowbray et al, 2001; Diaz-Canjela and Johnson, 2004). As Fox (2004:pg. 763) stated 'the bond of mother and child replaced my ache of having to take medication, of dealing with a deadly illness (schizophrenia)'. Other women also reported positive effects, such as giving up drugs and ending bad relationships (Mowbray et al, 2001).

2.6.5. Mothers with enduring mental health difficulties' experience of the mental health service

Although degeneracy theory has been discounted within the scientific literature, the idea of people with mental illness marrying each other and bearing children continues to be met with disapproval within society and, in particular, by health professionals. Mothers with a known diagnosis of mental health difficulties report being subjected to high levels of suspicion and surveillance from professionals who visited their homes. Despite this constant 'surveillance,' women do not consider mental health professionals very helpful in assisting them with their parenting role. The focus on the biomedical entity of mental illness and symptom reduction appears to overshadow professionals' understanding of women's experiences and needs as mothers (Oyserman et al, 2000; Montgomery et al, 2006). Health care professionals are perceived as having limited understanding of the distress of mothers, or the challenges they face trying to parent and maintain their mental health. While women described a range of practical and emotional challenges confronting them as parents, most had few discussions with health professionals on these issues. Women report that health professionals are more focused on their deficits as parents as opposed to capabilities, and on symptom control and drug compliance (Montgomery et al, 2006). Parenting role functions are often ignored in care planning and pre-discharge planning, with little attention given to the women's concerns around parenting (Gross and Semprevivo, 1989; Brunette and Dean, 2002). They also recounted incidents, particularly with General Practitioners, where their voice and expertise as mothers was dismissed, further undermining their confidence. Some women felt they were treated as the non-expert in relation to their child because they had a mental health difficulty (Nicholson et al, 1998c; Davies and Allen, 2007).

Although the literature emphasises the importance of health care staff talking to children about the parent's illness, or helping parents to do so, this did not appear to happen. Women frequently returned home from a stay within a mental hospital, to do what they had done before, and without any increased knowledge or skills in parenting (Diaz-Canjela and Johnson, 2004; Montgomery et al, 2006). Women also highlighted the tendency of services to withdraw any practical help offered as soon as an immediate crisis was resolved (Diaz-Canjela and Johnson, 2004). The frequent change in case worker and inconsistency between case workers were considered to militate against any continuity of care and emotional support (Mowbray et al, 2000; Diaz-Canjela and Johnson, 2004). Lindy Fox (1999), in her personal account, describes how health care professionals tended to view her children as the cause of her 'bipolar relapse', thus focusing health care on breaking up the family as opposed to advocating for services or developing a plan of care to keep her family. Overall, services were regarded as offering little continuing support to women who were struggling to look after children. Intervening in crisis when there was a child protection issue and deciding whether children should be taken away was seen as the main functions of statutory agencies (Diaz-Canjela and Johnson, 2004; Kessler and Ackerson, 2004; Montgomery et al, 2006).

Findings from studies that examined the social and clinical characteristics of mothers whose babies are supervised or removed, suggest that single women with a diagnosis of schizophrenia or other illness involving psychosis, living on low income or below the poverty line, and with low social supports are at particularly high risk of having their baby supervised by social services and/or raised by someone else (Miller and Finnerty, 1996; Howard et al, 2003; Hollingsworth, 2004). In one study, 50% of women with a diagnosis of schizophrenia and 10% of women with bipolar disorder in a South London mother and baby unit were discharged without their children, or discharged under formal supervision from child protection services (Kumar, 1995). In Dipple et al's (2002) study of women attending rehabilitation psychiatric services in Leicestershire (U.K.), 68% (37) of the mothers had at least 1 child they were permanently separated from before the child was 18 years old, and in 11 cases the separation occurred at birth. Only 3 of the 20 women with enduring mental health difficulties in Sands et al's (2004) study, in the United States, had full custody of all their children. The predominant pattern was for the children to be dispersed between a variety of settings – some with mother, father, grandparents, and other relatives, some in foster care, residential care and some adopted. Not surprisingly, a number of the mothers appeared genuinely bewildered about the custodial arrangements of their children and were unsure whether children in long term foster care had been adopted or if they were in a position to do anything to get reunited with their children. In all of the research the recurring theme was of women who felt controlled by a legal and psychiatric system that was insensitive to them as mothers and human beings.

Years after the separation, these women still spoke of their enduring sadness, pain and anger about their loss and were struggling to process and integrate their experience of being judged as an unfit mother (Miller and Finnerty, 1996; Joseph et al, 1999; Chernomas et al, 2000; Dipple et al, 2002). It is noteworthy that the vast majority of women in Joseph et al's survey (1999) felt it important to continue to be involved in raising their children, although the majority (88%) were not currently the primary caregiver, and requested help in getting their children returned to them. Those who had lost custody of their children even to family and friends suffered a powerful stigma associated with not being able to look after their children (Diaz-Canjela and Johnson, 2004). Some women felt the stigma and pain so strongly that they said they frequently lied, when asked if they had children (Chernomas et al, 2000). Although the pain and distress associated with the loss of children can negatively impact on the women's recovery, women in Diaz-Caneja and Johnson's (2004) study described a profound silence on the subject from mental health professionals. In some cases the woman's despair was interpreted as a symptom of illness (Fox, 1999). Nicholson (2005) suggests that, in the United States, child custody issues and the fear of loss of custody or contact with children is sometimes used as a leverage point to get women to comply with and participate in treatments. She highlights the need for further research into the prevalence, circumstances and impact of this ethically questionable practice. No studies were located that explored the impact of custody loss on women with mental health difficulties. The importance of this issue is highlighted by Swain and Cameron (2003) who point out that parents are often unrepresented in court proceedings, and it is seldom that formal court interventions are used to help parents to regain custody of their children. They argue that the assumption that parents with a mental health disability are unable to care for their children must be challenged.

2.7. Women with intellectual disabilities: pregnancy, childbirth, and early motherhood

2.7.1. Introduction

A thorough review of the intellectual disability literature yielded little published research specifically examining the experience of women/mothers with intellectual disability, but did provide an insight into the context within which pregnancy and parenthood in the intellectual disability population is viewed. Two key issues emerged, demonstrating that there are variations in the labels used to classify people with intellectual disability, and there is inconsistency in the defining characteristics under those labels. It was apparent, also, that there was an incremental development of thought around the issue of women with intellectual disability, with an almost chronological emergence of key themes focusing on the attitudes and response patterns to the ‘problem’ of women with intellectual disabilities; the realisation and acknowledgement that some people with intellectual disabilities had actually become parents; the presumption that parenting by such people was inherently inadequate; and the need to protect their children from abuse and neglect. These themes are described here to illuminate the context within which barriers and facilitators to maternity-related health of women with intellectual disabilities will be discussed in Chapter 6.

2.7.2. Labels, definitions and diagnostic criteria

2.7.2.1. Labels used to classify people with intellectual disability

‘Intellectual disability’ is one of a number of terms used internationally but is not universally agreed as being appropriate (Eastern Regional Health Authority (ERHA), 2002). The other most commonly encountered terms include: learning disability; developmental disability; mental and severe mental impairment; and mental retardation. The use of labels is somewhat dynamic; thus, in the past 25 years the United Kingdom has changed from ‘mental handicap’ to ‘learning difficulty’ to ‘learning disability’ whilst ‘mental and severe mental impairment ‘are the terms used within the United Kingdom mental health legislation (United Kingdom Parliament, 1983; Department of Health, 2001). In the past 15 years, Ireland (Government of Ireland, 1990; ERHA, 2002; Government of Ireland, 2005), Australia (Cocks et al, 1996) and New Zealand (New Zealand Ministry of Health, 2003) have changed usage from the terms ‘mental handicap’ and ‘learning disability’ to ‘intellectual disability.’ The ‘mental handicap’ label is contained within the current Irish Nursing Act (Government of Ireland, 1985; Keenan, 2007) but not in the more modern Disability Act (Government of Ireland, 2005). In the United States, ‘mental retardation’ is still widely used, although there is evidence within the literature of increasing use of the terms ‘developmental disability’ and ‘intellectual disability’ (Schalock et al, 2007; Wehmeyer et al, 2008). The American Association on Mental Retardation changed its name on 1st January 2007 to the American Association on Intellectual and Developmental Disabilities (AAIDD) (AAIDD, 2008).

In the past century and a half, additional social policy labels have applied to this group of people. These included terms such as 'developmentally disabled', 'feeble-minded', ‘idiot’, ‘imbecile’, ‘mental defective’, ‘mentally retarded’ and ‘vagabond’. (United Kingdom Parliament, 1913; Stainton, 1992; Trent, 1994; Cocks et al, 1996; Walmsley, 1997; 2000; Walsh and Gash, 2004; Grant et al, 2005). Gates et al (2007) adds ‘moral defective’ and ‘uneducable’ to this list.

The label utilised and what it means has varied over time and legislative boundaries. From the literature, it would appear that, as social policy shifted over the last century from care based on the bio-medical model, emphasising segregation and institutionalisation, to a social and rights based approach, the terms existing at the time became outdated and changed. Furthermore, negative overtones have developed around many of the labels that were previously used and so these have become unacceptable (ERHA, 2002; Gates, et al, 2007). Thus, for example, the previous medical and legal classifications ‘idiot’ and ‘imbecile’ (United Kingdom Parliament, 1913) are now generally considered to be insulting and undignified terms.

2.7.2.2. Defining characteristics and diagnostic criteria

While the label and meaning(s) attached to this heterogeneous group of people may vary over time and between societies, the general consensus in the published literature is that a number of commonalities exist (Gates et al, 2007; MacKenzie, 2007) and the following recurring themes have emerged (WHO, 1992 and 1993; Jenkinson, 1996; American Psychiatric Association, 2000; Scottish Executive, 2000; Department of Health, 2001; Welsh Office, 2001; ERHA, 2002; New Zealand Ministry of Health, 2003; Department of Health and

Social Services and Public Safety Northern Ireland, 2005; Salvador-Carulla, 2008):

- There is a below-average level of intellectual functioning (intelligence quotient of less than 70);
- There is a significant deficit in everyday living skills;
- The onset occurs before the age of 18 years.

In relation to diagnostic criteria and classifications of intellectual disability, the Diagnostic and Statistical Manual of Mental Disorders (DMSIV) TR Edition (American Psychiatric Association, 2000) and the International Statistical Classification of Disease and Related Health Problems 10th Version. (ICD 10) (WHO, 1992) are the most commonly used.

The Disability Act (Government of Ireland, 2005) uses the term ‘intellectual disabilities’, but does not define it. The Criminal Law (Sexual Offences) Act (Government of Ireland, 1993) uses the term ‘mental handicap’, but it also is not defined. However, Section 5(5) of the Act (‘Protection of mentally impaired persons’), does define the term ‘mentally impaired’, a heading which a small proportion of people with an intellectual disability may at times come under. In this section "mentally impaired" is defined as “suffering from 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.” (Government of Ireland, 1993:pg. 5(5))

There is one legal definition of intellectual disability in United Kingdom, found in the Mental Health Act (United Kingdom Parliament, 1983). However, this only defines people with intellectual disabilities (mental or severe mental impairment) who exhibit aggressive or seriously irresponsible behaviour (a minority of the intellectual disability population). According to Gates et al (2007), this is the first time in the United Kingdom that intellectual disability and mental ill health have been defined as separate legal entities.

Intellectual disability is therefore a contested label with variations in meaning. It could be argued that because of this and the fact that, as Clarke (2006) asserts, little is known of the perspectives of people with intellectual disabilities, serious hurdles exist in terms of understanding the limitations of health care provided and the development of more effective, quality services.

2.7.3. Historical perspective

2.7.3.1. Introduction

The literature demonstrated an incremental development of thought pertaining to the issue of women with intellectual disability. Themes emerged chronologically, describing the attitudes and response patterns to the ‘problem’ of women with intellectual disabilities. Typically, these patterns centred firstly on the congregation and segregation of women (and men) with intellectual disabilities followed by the realisation and acknowledgement that some people with intellectual disabilities had, in fact, become parents. This gave rise to the perceived need to control the reproductive capacity of such women through their sexual segregation or, indeed, sterilisation. It was presumed that, where women with intellectual disabilities became pregnant, their parenting would be inherently inadequate, legitimising the need to protect their children from expected abuse and neglect. Whereas it may be considered that societal attitudes have shifted considerably, it is interesting to note that the pregnancy and maternity-related health needs of women with intellectual disabilities remain largely unaddressed. Three important historical themes, eugenicist policies, the presumption of parental inadequacy, and negative attitudes to the sexuality and reproductive rights will be addressed within the context of their role as barriers and facilitators to the maternity-related health of women with intellectual disabilities.

2.7.3.2. Attitudes and response patterns to the ‘problem’ of women with intellectual disabilities

Initial concerns regarding the ‘problem’ of women with intellectual disabilities emerged from the amalgam of religion, positivism and science that constituted 19th century eugenics. This movement sought to stem the ‘multiplication of the unfit', and their perceived threat to society (Sheerin, 1998a). Indeed, the eugenicists deeply held the belief that 'all poor, feebleminded women at large become mothers of illegitimate (feebleminded) children soon after reaching the age of puberty' (Neff et al, 1915 cited in Brandon, 1957a:pg. 711), and that the multiplication of the 'unfit' threatened humanity with 'economic and biological disaster' (Tredgold, 1929 cited in Brandon, 1957a:pg. 711).

The focus centred directly on one specific group: poor, intellectually disabled women of childbearing age. The responses to this were *prophylactic institutionalisation* - segregating the intellectually disabled women from society - and *prophylactic sterilisation* - removing from them the possibility of having any reproductive future (Pfeiffer, 1994). Rafter (1992) argues that the eugenics movement in the United States, under the leadership of Josephine Lowell, proceeded to the point of actually criminalising the very fact of being female and intellectually disabled. Scior (2003) suggests that, for these women, gender and disability became inextricably linked. Whereas the eugenicist perspective may be considered to be one that pervaded late 19th and early 20th century thought, its role in the development of services was so pervasive and important that many services and indeed, Western society itself, Sheerin (2006) argues, has found it difficult to discard its remnants. According to Stansfield et al (2007) this is evident in the continuance of segregation and, until recently, even sterilisation of people with intellectual disability in the United Kingdom. Broberg and Roll-Hallson (2005) comment similarly on other countries. Stehlik (2001) argues that such actions are examples of an increasing trend of 'corporate/neo-eugenics'.

2.7.3.3. The presumption of parental inadequacy: protecting the children

Despite all attempts to remove the procreative capability of women with intellectual disability, it became clear that the eugenic policies were not achieving their aim. This failure is evident in the literature of the mid-20th century, which increasingly focused on the reality that some women with intellectual disabilities, both in institutions and in society, were becoming pregnant and giving birth to children (Hathaway, 1947; Mickelson, 1947, 1949;

Brandon, 1957a, 1957b). This realisation did not, however, bring about a significantly changed attitude towards women with intellectual disability (Abramson et al, 1988), but rather refocused the attention on efforts and strategies to deny their parenting capability. Thus, Espe-Sherwindt and Crable (1993) argue that several myths developed around the reality:

- That the children of intellectually disabled parents will be themselves intellectually disabled;
- That intellectually disabled parents will have more children than, on average, the norm;
- That intellectually disabled parents provide inadequate parenting;
- That parents with intellectual difficulties cannot learn adequate parenting skills.

It is likely that these issues served to re-instil the fear that was inherent in eugenic thought (as is clear from the first 2 statements), whilst introducing a further concern regarding the security of children born to persons with intellectual disability. Whereas the first and second issues were quickly disproved (Brandon, 1957a; Reed and Reed, 1965; Gillberg and Geijer-Karlsson, 1983; Koller et al, 1988), fears regarding the adequacy of parents with intellectual disabilities remained, and probably still remain, in question (Fantuzzo et al, 1986).

It is clear from the literature that many such people are striving to provide for their children, often in very difficult situations, and a significant number of these parents are mothers, parenting alone following either abandonment or sexual assault. A critical review of the literature found that the effects of sexual violence against women with intellectual disability appeared to be comparable to those experienced by similarly traumatised women in the general population. Aggression and self-injury were sometimes exhibited and psychiatric symptoms included depression, anxiety and indicators of traumatic stress reaction (Sequeira and Hollins, 2003). Struggling with the after-effects of such trauma could, understandably, prevent women with intellectual disability from displaying adequate parenting. It is recognised that amongst women with intellectual disability who are parenting alone, there is a tendency towards poorer health (IASSID SIRG, 2008), which could also hinder the quality of their parenting activities.

Keltner et al (1995) suggest that not only is there a lack of support, but barriers exist to these women accessing public service supports, including the fear of their children being taken into care, and lack of accessible information. Keltner et al (1999) however, in a study of child outcomes, which attempted to remove poverty as a confounding factor, suggest that poverty is not the main factor in this regard. Further research is needed in this area but, whatever the causes, what emerges from the literature is that mothers with intellectual disabilities often struggle against numerous disadvantages to provide adequate parenting, yet many succeed. An explorative study found that around 1.5% of persons with intellectual disability in the Netherlands were parents, mostly those with mild disabilities. In the eyes of their professional care-givers, 33% were definitely “good enough” parents, 51% were “not-good-enough” parents and in the remaining 16% there was no clear decision. The authors identified that a high quality social network, acceptance of the parents in the community and their ability to follow advice were key elements to success in parenting (Willems et al, 2007).

The impact on children of parental inadequacy among parents with intellectual disabilities has been widely studied (Brandon, 1957a and 1957b; Borgman, 1969; Gath, 1988; Pixa-Kettner, 1999; May and Simpson, 2003). Amongst the effects identified are neglect (Crain and Millor, 1978; Katz, 1992), abuse (Helfer and Kempe, 1974; Schilling et al, 1982), and inadequate or inappropriate nutrition (McConnell and Llewellyn, 2000). It is not clear, however, whether these child outcomes are related solely to parental inadequacy or to the situational poverty and lack of support that is frequently the backdrop to such parenting (McConnell and Llewellyn, 2000). It has also been shown that there is a higher prevalence of unrecognised medical problems and developmental delay due to inadequate early stimulation in the children of parents with intellectual disabilities (Feldman et al, 1985). Again, it is difficult to relate this directly to the adequacy of the parenting provided, and studies suggest that these are, rather, related to lack of support and difficulties in accessing services and information (Keltner et al, 1999; McConnell and Llewellyn, 2000; IASSID SIRG, 2008; Mayes et al, 2008). This view is supported by the fact that many interventional studies providing parenting training and support have been found to improve parenting outcomes (Feldman et al, 1985; Tymchuk, 1985; Fantuzzo et al, 1986; Tymchuk et al, 1988; Llewellyn et al 2003).

The immediate response to potential or actual inadequate parenting by parents with intellectual disabilities has, in the past, involved the almost systematic removal of children from the parents' custody (McConnell and Llewellyn, 1998; Sheerin, 1998b; Glaun and Brown, 1999); this is evidenced by the findings of Mickelson (1949) and, more recently, those of Accardo and Whitman (1990). In particular, it is the fact that over one fifth of families in this latter study, who had children removed from them, had provided satisfactory care, which causes concern. Feldman (1986:pg. 778) concludes that ‘retarded parents are probably currently the only group of citizens whose children are routinely taken away at birth, before any evidence of child maltreatment can be established to justify apprehension.’

2.7.3.4. Attitudes to the sexuality and reproductive rights of women with intellectual disabilities

Women with intellectual disability are often considered either asexual or hypersexual, with little or no ability to control their sexual expression, yet they have the same sexual needs and desires as people without intellectual disabilities (Mitchell et al, 1978; Aunos and Feldman, 2002; Keenan, 2006b). However, through the ages, women with intellectual disabilities were perceived as ‘the most serious threat to society’ (Trent, 1994:pg. 179), because they were viewed as abnormally fertile women who gave birth to defective children and spread sexually transmitted diseases (Jones, 1986; Perkins et al, 2002), therefore making them subjects ‘to be dealt with’ (Mental Deficiency Act, 1913 cited in Walmsley, 2000:pg. 65). They were often separated by sex or sterilised to prevent procreation (Stainton, 1992; Trent, 1994; Cocks et al, 1996; Walmsley, 2000; Black, 2003; Broberg and Roll-Hansen, 2005; McClimens, 2005; Keenan, 2006a).

Walmsley (2000) has found evidence in Bedfordshire 1916-1918 to indicate that women with intellectual disability were more likely to be institutionalised and their sexual conduct was a major factor in this decision. Perkins et al (2002) suggest that the extended families of mothers with an intellectual disability are often the subject of discrimination, with the disability of their relative perceived as an individual pathology to be dealt with by medicalising and hospitalising them (Oliver, 1990; McClimens, 2005). Such women were also viewed as a social problem and the focus of rehabilitation (Simmons, 1978; Trent, 1994; McClimens, 2005; Keenan, 2006a).

2.8. Summary

Against a background of increasing medicalisation of childbirth, where women with disabilities may be at risk of being viewed through a medical lens solely because of their particular disability, the various aspects of different disabilities were examined. The historical development and improvement of national data collection and statistics is noted and should provide more useful data in the future. Within the limits of the published research, the background and context for the care of women with all types of disabilities showed a history of discrimination lasting to the present day. Evidence from the literature suggests that society has, in many instances, undervalued women with disabilities, has exerted control over their sexual and reproductive lives and has, at least in the case of women with mental health difficulties, exacerbated their difficulties. Mothers with intellectual or mental health disabilities, in particular, are often separated from their children, despite a lack of evidence of harm or the existence of positive benefits to them of performing the mothering role. Societal attitudes such as these may very well lead to barriers for women with disabilities in accessing suitable services in pregnancy, childbirth or motherhood. The following chapters examine this issue in detail, and identify both barriers and facilitators that exist for these women.

Section Two: Presentation of analysis of literature

Chapter Three: Women with physical disability: barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood

3.1. Introduction

3.1.1. Overview of section

The focus of the next section of the review (Chapters 3 – 6) is to identify and present a comprehensive report of the barriers and facilitators experienced by women with a disability (physical, sensory, mental health or intellectual) as they access and use the maternity and healthcare services during pregnancy, childbirth and motherhood. Firstly, a definition of 'access to services' in the context of women with disabilities of all kinds is provided, thus setting the scene for the presentation of a detailed exploration of facilitators and barriers to access of services in this and succeeding chapters.

3.1.2. Overview of chapter

Chapter 3 presents the experiences of women with a physical disability. Initial sections of this chapter present the barriers to accessing services, as identified from 27 published research papers (Appendix 3, Table 2), in terms of accessibility, accommodation and acceptability of services. A final section describes facilitators to access, under each of these headings that were noted in 8 publications (Appendix 3, Table 3).

3.2. Defining 'access to services'

The Commission on the Status of People with Disabilities (1996) argued that people with disabilities have a fundamental right to a health service which is accessible, equitable, individual centred and responsive to their particular need. Furthermore, positive health outcomes and social gain for women with disabilities are dependent on accessible and appropriate health care and the provision of adequate health information to woman during pregnancy, childbirth and early motherhood.

Access is a multidimensional concept with 5 distinctive dimensions, incorporating both the potential to obtain and the actual receipt of health care (Aday and Andersen, 1984). It encompasses more than just access to the physical environment; it also includes access to health information and effective communication between health professionals and women. Women with disabilities report insufficient access to health care services (Fouts et al, 2000). They encounter substantial challenges, which impact significantly on their ability to access care. These challenges are varied and can be categorised as physical, attitudinal, communicational, informational and financial (Thierry, 1998). The term access has multiple meanings and a precise definition is difficult to find. The Oxford Dictionary describes the term as 'the action of going or coming to or into; coming into the presence of, or into contact with; approach, entrance and the habit or power of getting near or into contact with; entrance, admittance, admission' (Oxford Dictionary, 2008). Words synonymous with the term include 'coming to or towards and approaching'. Terms such as access, availability and acceptability are often used interchangeably.

Many researchers (Aday, 1975; Penchansky and Thomas, 1981; Parish and Huh, 2006) attempt to define, refine and interpret the concept which has resulted in the development of many different interpretations. Such interpretations range from the potential to obtain available resources and services to ensuring equal use of services for equal need. The use and relativity of the services forms the basis of Aday's (1975) definition. The author contends that a 'lack of access occurs when there is a need for the services but these services are not being utilised' (Aday, 1975:pg. 221). However, Penchansky and Thomas (1981) extend the definition further and suggest that access is a measure of the degree of 'fit' between the characteristics and expectations of the person and characteristics of the health care services. Parish and Huh conclude that it is the 'timely utilisation of services to achieve the best possible health' (Parish and Huh, 2006:pg. 7). A commonality in all definitions is that the concept is dependent on the person's ability and willingness to enter into the health care services (Penchansky and Thomas, 1981).

Penchansky and Thomas (1981) suggested how the concept has 5 reasonable and distinctive dimensions which are interrelated and not easily separated. The dimensions are:

- Availability, which refers to the relationship between the extent and type of services available to address women's needs;
- Accessibility, referring to the relationship between the location of the women and the location of the services;
- Accommodation, which is the relationship between the service providers and the organisation of resources to accommodate women;
- Affordability, referring to the women's ability to afford the services;
- Acceptability, which refers to the relationship established between health services providers and the women.

Challenges encountered in any of these 5 component dimensions will impact significantly on women in 3 distinctive ways – a decrease in the utilisation of services, dissatisfaction with the services and care received and an inequality in service provision (Penchansky and Thomas, 1981). Availability and affordability have much the same challenges for able-bodied women as for those who are disabled, with the exception that many disabled women are unemployed and therefore are less likely to be able to access private care. The challenges and barriers experienced by women with physical disabilities when accessing health services during pregnancy, childbirth and early motherhood are described in more detail under the remaining 3 headings.

3.3. Barriers to accessibility of services for women with physical disabilities

3.3.1. Location of services and models of care

The Maternity and Infant Care Scheme provides a programme of care to all women in Ireland during pregnancy, childbirth and early motherhood, and ensures that care administered through the public system is delivered with no financial cost incurred by women. Accessibility of health care is determined, however, by the location of services. Services that can be accessed by public transport, are located in the local vicinity and flexible in the provision of care are more accessible for women with disabilities.

In the western world, most women now give birth in hospital. Although the reasons for the move from home to maternity hospital in Ireland are multi-faceted, they are undoubtedly influenced by Department of Health and Children policy to centralise services (Kennedy, 2002), thus providing units of a minimum critical size. This ensures that specialist staff receive sufficient experience to maintain skills in diagnosis and treatment of rare complications but inevitably means that some women will live at a distance from the nearest maternity unit.

In Ireland there are 19 maternity hospitals and 2 midwifery-led units that are responsible for the provision of publicly-funded health care to women during pregnancy, childbirth and early motherhood. In addition, independent midwives can be contracted by any woman planning to have a home birth. The hospitals are geographically spread throughout the country and are generally located in densely populated urban areas. This regionalisation of maternity and perinatal centres, is designed to enable a range of specialist staff to be employed and available, and offers sufficient experience in identification and treatment of more rare conditions or complications. However, O'Doherty and Regan (2006) argue that the policy reduces the availability of alternative models of care and the proximity of services to women as some women are required to travel up to 80 kms to the nearest maternity unit (Sheeran, 2007). The organisation and models of care are not uniform or standard among these hospitals. In addition to the 2 midwifery-led units, 4 out of the 19 hospitals offer community based services, for example, Domino and Community Midwives schemes. These schemes afford a woman who is classified as having a 'low risk' pregnancy the opportunity to access care in the community or in her own home. Depending on the model of care on offer the woman may also give birth at home. Some hospitals provide an alternative model called the 'early transfer home' service/scheme where mothers and babies are discharged from the hospital 6 hours after the birth and a team of midwives provide midwifery care for the subsequent 5 days in the woman's own home. To be eligible for this scheme the mother and baby must have had an uncomplicated birth and immediate postnatal period.

3.3.2. Transport

Driving independently may not be an option for some women with a physical (or sensory) impairment so they are reliant on public transport, taxis or other individuals when travelling to and from health care facilities (Anderson and Kitchin, 2000; Lawthers et al, 2003; Prilleltensky, 2003; Scheer et al, 2003). Depending on the woman's geographic location and the availability of suitably adapted public transport, access to health care facilities and participation in other community activities may be severely curtailed. In the United States, it is estimated that 1 in 4 women with disabilities have no access to appropriate transportation (Nosek, 1992; Goodman, 1994). Inadequate transport to and from the health care facilities can pose significant challenges for women trying to get to appointments and to access reproductive care. Even when public transport is available Smeltzer et al (2007) report how, in the United States, it is expensive, undependable and inadequately equipped to accommodate or secure women with a wheelchair (Smeltzer et al, 2007). Long waiting times for suitably adapted transport to arrive is the norm and can be problematic when appointment times are inflexible. The service is generally infrequent and the distance of health care facilities from designated bus stops may be such that women still need to negotiate many other challenges in the environment before reaching the health care facility.

For women who use private transport but are unable to drive themselves, a partner, family member, friend, or personal assistant is needed to ensure appointments are kept. Here extensive advance planning is required and often appointments need to be scheduled around the driver's availability. However, accommodation of these requirements and flexibility in the scheduling of appointments is not a consideration experienced by women. Appointments are generally arranged around physician's and/or consultant's schedules and it can be difficult to obtain an appointment outside the scheduled hours (Clark, 2002). Waiting times for appointments are generally reported as too long (O'Doherty, 2006) and women's complex needs, which warrant assistance and extra time (Schopp et al, 2002; Women's Health Council (WHC), 2004) are rarely considered or accommodated when interacting and interfacing with health professionals (WHC, 2004).

3.3.3. Physical environment

3.3.3.1. Access to buildings

The design of the built environment can be another critical determinant of accessibility and impacts significantly on the social inclusion and participation of women. For some women physical accessibility to the building is often the first and most obvious challenge encountered (House of Commons Health Committee, 2003; Thierry, 2006) and can be one of the most challenging aspects to obtaining care (Schopp et al, 2002). Access to the built environment is legislated for in the Disability Act (Government of Ireland, 2005) and Part M of the Building Regulations (Department of Environment and Local Government, 1997, 2000). The Disability Act (Government of Ireland, 2005) and the Equal Status Act (Government of Ireland, 2000) require that all service providers 'where practicable and appropriate' (Disability Act (Government of Ireland, 2005:pg. 27)), make reasonable accommodation for all people with disabilities. Women with disabilities require information about accessible services and resources but information on the number and location of accessible health care facilities and physician's practices is not readily available (Clark, 2002; Pierce, 2003).

Evidence suggests that a substantial proportion of health care facilities and physician's offices are inaccessible to women with a physical or sensory disability (Campion, 1997; Welner, 1997; Grabois et al, 1999; DeJong et al, 2002; Smeltzer et al, 2007). It is estimated that 2 out of 5 women with disabilities experience difficulty getting into and around the built environment of physicians' offices (Goodman, 1994) while a fifth of women in both the United Kingdom and the United States report that due to architectural barriers, health care facilities are unable to accommodate them during childbirth (Goodman, 1994; Nosek, 1996). Other obstacles that render health care facilities, physician's offices and clinics inaccessible include the physical location of facilities, offices and clinics, non availability of designated parking bays and the topography of pavements and curbs (Thomas and Curtis, 1997). For some women the stress and physical energy generated from trying to gain access is so intense that some would *'delay appointment making'* (Scheer et al, 2003:pg. 227) rather than try to negotiate access to an inaccessible environment (Goodman, 1994; Nosek et al, 1995; Scheer et al, 2003). This is compounded even further as health professionals are often unaware of the problems that inaccessible offices and clinics present (Smeltzer et al, 2007). Physical challenges which impede access convey the impression to women that they are unwanted, unwelcome and are a burden on health care providers (Kaplan, 2006).

3.3.3.2. Internal architecture

Internally waiting areas and rooms pose physical challenges with inaccessible bathroom facilities, inadequate space and narrow corridors posing difficulties for women with disabilities especially when trying to manoeuvre in a wheelchair. Reception desks are at an inappropriate height or level to facilitate eye to eye contact (McKay-Moffat, 2007) and the exchange of personal and sensitive information with receptionists, who are often perceived as gatekeepers to the services. Space restriction limits any freedom of movement and limits the women's possibility to move around the built environment, which essentially restricts them to one particular area.

Some health care units in Ireland have been described as substandard, with significant infrastructural deficits (Institute of Obstetricians and Gynaecologists Subgroup, 2006). In some units the infrastructure and the configuration of the buildings are so constrained that it impedes the delivery of optimal services. Inadequate facilities and insufficient consultant, midwifery and nursing staff levels (Institute of Obstetricians and Gynaecologists Subgroup, 2006) cause clinical risk management issues and the capacity constraints have led to overcrowded, unsafe environments, which impact on the access and the quality of service delivery for all women (Health Service Executive, 2005). Health services are only rendered accessible by the informal actions of relatives and friends who compensate for the 'deficiencies, inefficiencies and injustices' (D'Eath et al, 2005:pg. 4) of the services. Service inadequacies may thus be masked where friends or relatives compensate for gaps. Access to basic facilities e.g. toilet and bathing facilities can be problematic (McFarlene, 2004) and some women, in consequence, are upset and feel marginalised by the failure to meet these basic needs.

3.3.3.3. Inadequate collaboration of services

Women with disabilities frequently encounter fragmented and uncoordinated services (Commission on the Status of People with Disabilities, 1996;

Department of Health, 1996; Baker et al, 1997; Thomas and Curtis, 1997). Services that are fragmented and uncoordinated are insensitive to individual needs and service provision is often compromised (Thomas and Curtis, 1997; D'Eath et al, 2005). Health professionals in maternity services may work in isolation from other professions or staff involved in the care of the women with a disability; there is little collaboration with other professionals to assist them to become knowledgeable about the disability, and a referral to allied health professionals, for example, physiotherapists or occupational therapists, is an uncommon occurrence (Lipson and Rogers, 2000; McGuinness, 2006). Consequently, health professionals do not offer effective, individualised and culturally sensitive care or proactive help and guidance (Tingle and Dunmore, 2005).

3.3.3.4. Lack of suitable equipment

It is also difficult for women with disabilities to use equipment that is fixed and not readily adjustable, for example, examination tables and impractical baby cots, and many women rely on health professionals to help negotiate such inaccessible equipment (Thomas and Curtis, 1997). However, these women frequently experience a lack of will, manpower and suitable equipment to help transfer them safely in order that examinations can occur or in order that they can interact with their baby. A recent study of 152 trusts[3] providing obstetric or midwifery-led maternity services in England found that 83% of trusts reported having height-adjustable couches available at some antenatal clinics and 90% said they would provide home visits for disabled women. However, only 22% of delivery units had flexible-height cots (Commission for Healthcare Audit and Inspection, 2008).

Inappropriate training of health professionals in correct manual handling techniques exacerbates the issue of safe transfer even more and exposes women to impractical and unsafe techniques (Grabois, 2001). Diagnostic

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[3] Health service provision in England occurs within designated Trusts that divide the country into a number of areas.

equipment can also be a source of discomfort and its use can be a daunting and traumatic experience for some women, especially those with a physical disability, and their experience may deter these women from seeking further care (Goodman, 1994; Welner, 1999).

3.3.3.5. Lack of assistance with physical environment

An inaccessible environment coupled with a lack of accessible baby equipment and inflexible hospital guidelines, procedure, policies or protocols impact on women's ability to care for their babies in a confident and independent manner. McFarlene found that health professionals are often unable or fail to suggest creative and practical solutions to overcome the challenges encountered with an inaccessible environment and equipment (McFarlene, 2004). They fail to provide alternative equipment solutions, or to refer the women to appropriate services from where adapted/modified equipment may be purchased (Lipson and Rogers, 2000).

Access to high quality personal care attendants could facilitate independence in women with disabilities (Lawthers et al, 2003); however, some women in the United States experience difficulty in finding suitably trained and experienced personal care attendants. Limited numbers of competent attendants impact on the women's autonomy and ability to be independent and render the individual dependent on formal and informal support structures such as partner, their children and extended family (D'Eath et al, 2005).

3.4. Barriers preventing accommodation of women with physical disabilities

3.4.1. Access to health information

Possessing information engenders a sense of autonomy and control and is a central tenet of the decision making process; Clark (2002:pg 10) suggests that it is in fact 'the fourth right of citizenship'. Insufficient access to information excludes women from the process of informed decision making and impacts significantly on their choice. Moreover, it impinges on the doctrine of informed consent where women must understand all risks and benefits associated with procedures and care (Grabois, 2001; D'Eath et al, 2005). Not having adequate explanation especially about invasive, intimate procedures renders women more vulnerable and when the procedures are conducted they may feel undignified, humiliated and degraded.

The information needs of women with disabilities are varied and dependent on the type of disability or impairment experienced (McKay-Moffat, 2007). Women with disabilities, however, do experience difficulties in receiving quality health information (Nosek, 1992; Harris and Bamford, 2001; Commission for Healthcare Audit and Inspection, 2008) and Campion (1997) and the Royal College of Nursing (RCN) (2002) found serious deficits in the provision of information in relation to pregnancy, childbirth and disability in the U.K.. When provided, the information tends to be irrelevant, inadequate, unhelpful (Goodman, 1994; Commission for Healthcare Audit and Inspection, 2008) and contradictory (Thomas and Curtis, 1997). Women are forced to obtain information from other sources, e.g. support groups/networks and voluntary agencies while many parenting skills are developed through experiential learning (Thomas and Curtis, 1997).

3.4.2. Antenatal education classes for women with disabilities

The learning needs of expectant women with physical disabilities vary considerably more than for women without disabilities and contemporary models of antenatal education have been described as inappropriate (Conine et al, 1986; Blackford et al, 2000). The evidence suggests that the needs of women with disabilities are not being met when attending antenatal classes (Conine et al, 1986; Blackford et al, 2000; Commission for Healthcare Audit and Inspection, 2008). Some women reported that class facilitators do not advocate for women with disabilities (Blackford et al, 2000) and described them as cold and uncaring (Westbrook and Chinnery, 1995). Westbrook and Chinnery (1995) found that many facilitators lack knowledge in relation to disability and pregnancy and fail to consider the special needs of women with physical disabilities. Some facilitators consider that the provision of antenatal education classes for women with disabilities is not part of their role and function (Conine et al, 1986) and have indicated how the provision of adaptive programmes for women with disabilities is time-consuming and disruptive to normal progress (Conine et al, 1986). In a recent survey of the 152 trusts providing maternity services in England, pre-pregnancy advice clinics were available for women with a physical disability in only 19% (Commission for Healthcare Audit and Inspection, 2008).

Conine et al (1986) found that many of the environments where antenatal classes are held are inaccessible; doors, walkways and bathroom facilities are generally inappropriate and directional guides indicating the location of appropriate facilities are non-existent. There is a lack of sufficient information in appropriate formats which could help to facilitate a state of independence (Blackford et al, 2000) and facilitators do not discuss adaptive techniques that could help women with disabilities in their parenting skills. Lipson and Rogers (2000) and McKeever (2003) found that facilitators did not routinely provide alternative equipment or refer the women to appropriate services from where adapted/modified equipment may be purchased.

Teaching and learning resources used by class facilitators are more suited to women without a disability and are inappropriate for women with a physical (or sensory) impairment. The stigma of having a disability impacts on women’s sense of self and self-confidence. Consequently women may lack the confidence to discuss their particular concerns and issues with class facilitators. This often results in many women not accessing and availing of antenatal education classes or, when they do, women are unwilling to voice concerns or simply ask a question because the educator and other women with no disability in the class cannot relate to or associate with their anxieties or fears. Women therefore feel excluded from the class (Westbrook and Chinnery, 1995).

3.4.3. Ineffective communication between health professionals and women with disabilities

Some health professionals communicate with women with disabilities in a patronising (D'Eath et al, 2005) or authoritarian (Westbrook and Chinnery, 1995) manner. Campion (1997) reports that the language used by many health professionals reflects their prejudicial attitudes and ignorance and may leave women feeling fearful, uncomfortable and degraded. Even the physical positioning of health professionals in clinic areas reduces good communication, for instance, due to lack of eye to eye contact between a wheelchair user and those standing near them (McKay-Moffat, 2007).

3.5. Barriers to acceptability of services for women with physical disabilities

3.5.1. Attitudinal challenges from health professionals

Inappropriate attitudes, behaviours and a lack of awareness (Nosek, 1992; House of Commons Health Committee, 2003; RCN, 2007) are the most significant subtle challenges encountered by women with disabilities when accessing health care during pregnancy, childbirth and early motherhood and are the most difficult to address and overcome (Schopp et al, 2002). Women with a disability will have very diverse backgrounds and different experiences and the disability will impact differently on the lives of each individual. When health professionals are unable to recognise and embrace this diversity it has a profound impact on the development of attitudes and whether or not women access the health care services (Kallianes and Rubenfeld, 1997; Shakespeare, 2000).

3.5.2. Staff attitudes and behaviours towards women with disabilities

3.5.2.1. Attitudes and behaviours regarding sexuality

The many myths and misconceptions surrounding women with disabilities have resulted in the construction of negative prejudicial attitudes towards them, and hostility, sympathy and pity are common associated emotions (DeLoach, 1994).

These emotions and prejudicial attitudes heighten women's sense of vulnerability, insecurity, isolation and marginalisation and increase the pressure experienced by women as they embark on, and attempt to negotiate, the many challenges of pregnancy (McGuinness, 2006). One prominent myth is that women with disabilities are asexual (NWCI, 2006), uninterested in sex or are unable to part take in sexual activity. This assumption is 'pejorative' (Kaplan, 2006:pg. 450) and may result in health care providers denying access to appropriate services and care. The assumption is also untrue, as women with physical disabilities are sexual beings who engage in sexual activity. They, too, experience feelings of desire and love, seek sexual gratification and desire motherhood (Anderson and Kitchin, 2000). Vansteenwegen et al (2003), however, note how some women with a physical disability tend to reject their sexuality, around which there is a great deal of negativity, prejudice and misunderstanding (Nisha, 2005).

Lee and Oh (2005) highlighted a range of barriers experienced by married women with a physical disability with regard to obtaining sexual and reproductive health care information. Barriers included lack of knowledge among health care professionals and the absence of medical facilities for people with disabilities. Many women in this study (n=410) reported not using safe sex devices and 25% had insufficient information regarding sexuality and reproductive health.

3.5.2.2. Attitudes and behaviours relating to pregnancy

Becoming a mother is an aspiration of many women with a physical disability, which, according to Mc Keever et al (2003) represents the 'capturing of a gender or recapturing of a lost gender' (Mc Keever et al, 2003:pg. 671) and provides women with a sense of normality. It is an avenue to societal acceptance, as becoming a parent shifts the focus from the disability to parenting and provides women with a platform that emphasises their independence and competency (Grue and Tafjord-Laerum, 2002). Pregnancy and parenthood is thus perceived as a triumph over their disability (Goodman, 1994). However, many women with physical disabilities planning to become pregnant are exposed to prejudicial attitudes of others and experience tremendous pressure not to do so (Baker et al, 1997; House of Commons Health Committee, 2003; Prilleltensky, 2003; McFarlene, 2004; Thierry, 2006). These attitudes are quite often founded upon, and impregnated with, a eugenic philosophy and ethos and are described as dehumanising (Grabois, 2001). Consequently, women may forgo pregnancy and parenting because they fear that their disability will be inherited by their child or that the child may be psychologically deprived or burdened by the fact that one or both parents have a disability (Carty, 1998). Health professionals sometimes label women with disabilities as having an unwanted, unplanned pregnancy and desiring a termination, which exemplifies their assumption that women with disabilities are incapable of becoming a parent (Welner, 1997; Carty, 1998; Prilleltensky, 2003).

Women with physical disabilities have described health professionals as aloof, authoritarian and domineering (Westbrook and Chinnery, 1995) or patronising, hostile and unable or unwilling to accommodate diversity (D'Eath et al, 2005). The hypervisibility of the woman's disability may result in the woman being shunned or ignored (Zitzelsberger, 2005), although this may be due, in part, to health professionals' nervousness at the different challenges that women with disabilities (Goodman, 1994) present.

3.5.2.3. Attitudes and behaviours postnatally

Having a physical disability and needing help are in contrast to the normal representation of mothering (McKeever et al, 2003) and health professionals may find it difficult to comprehend these women's ability to mother, nurture and care for their baby (McFarlene, 2004). Women with physical disabilities describe how they perceive themselves to be constantly judged and scrutinised by health professionals and are fearful that they would be considered a failure (Prilleltensky, 2003; McFarlene, 2004). Many are afraid to ask for assistance as they fear that such a request would be interpreted as them being incapable and unable to cope with the functions of their new role (Thomas and Curtis, 1997; McKeever et al, 2003; McFarlene, 2004). Health professionals often interfere and provide unhelpful advice and care which only reinforces the woman's sense of difference and signals their inadequacy (Thomas, 1997). Frequently, alternative solutions offered or proposed by women that could help them master the skills associated with practical baby cares are considered inappropriate by health professionals (Thomas, 1997) and they fail to appreciate women's expertise in mastering and adapting to their disability.

3.5.3. Effect on women of negative staff attitudes and behaviours

Such prejudicial attitudes combined with insensitive and derogatory comments only serve to diminish a woman's self-esteem and self-efficacy and cause her to doubt her own ability to be an effective mother (Welner, 1997). This erodes women's sense of autonomy and empowerment and they become passive and compliant in their interaction with health professionals (Prilleltensky, 2003), describing how they feel depersonalised and a burden on the health services (Smeltzer et al, 2007).

The literature demonstrated clearly the strong emotions such as anger and bitterness, expressed by women with physical disabilities, which emanates from their feelings of isolation and exclusion (Tilley, 1998). These feelings arise in response to the assumption that their traditional roles as nurturers, mothers, wives, homemakers, and lovers are not considered appropriate for them; instead society perceives stereotypes and portrays them as dependent and asexual individuals (Tilley, 1998). Moreover, many women may feel disabled, demoralised and 'at the mercy of a fragmented, medicalised system' (WHC, 2004:pg. 13), which erodes their sense of individualism. In a recent study of 152 trusts providing obstetric or midwifery-led maternity services in England, where over 26,000 women responded to a questionnaire survey, women who described themselves as having a disability responded more negatively to questions on the quality of care at all stages of pregnancy, birth and the postnatal period. They were also less positive in their responses regarding being treated with respect and dignity, and on those concerning the receipt of enough information (Commission for Healthcare Audit and Inspection, 2008).

3.5.4. Lack of knowledge of disabilities in health care professionals

3.5.4.1. Lack of knowledge in health care professionals resulting in avoidance of women with disabilities

The negative attitudes from health care professionals described above may stem from the health professional's lack of awareness, knowledge and expertise in relation to the disability (House of Commons Health Committee, 2003). Few health professionals seem knowledgeable about the care required by women with disabilities and many are unfamiliar with disability related complications that may develop (Westbrook and Chinnery, 1995; Lipson and Rogers, 2000; McGuinness, 2006; Thierry, 2006; Smeltzer et al, 2007). They may lack awareness of, and therefore be insensitive to, the individual needs of women. Quite often it is the woman who educates the health professional about her disability. This lack of knowledge and awareness leaves many health professionals anxious, uncomfortable and nervous about caring for a woman with a physical disability during pregnancy, childbirth and early motherhood (Baker et al, 1997), which may encourage them to refer women to another physician. This action impacts on the concept of continuity of care (Grabois et al, 1999; House of Commons Health Committee, 2003), a concept that could help alleviate the many attitudinal challenges experienced by women.

Furthermore, the evidence suggests that women with physical disabilities find it extremely difficult to locate a physician with the knowledge to manage the disability and the pregnancy (Nosek et al, 2001; Veltman et al, 2001; House of Commons Health Committee, 2003). Many physicians perceive the pregnancy to be high risk, unusual and problematic (Thomas, 2001). For some women, disability does increase the risk of developing secondary complications; however, labelling the pregnancy as high risk results in increased frequency of antenatal visits, consequently women are 'compartmentalised and labelled as deviant from the norm' (Prilleltensky, 2003:pg. 29). Evidence also suggest that some physicians employ discriminatory actions (Grabois et al, 1999) by developing an eligibility criterion that excludes women with a disability or by failing to modify policies, practices or procedures that would ensure the inclusion of women with disability and facilitate access to their services.

3.5.4.2. Lack of knowledge in health care professionals resulting in inappropriate care

Health professionals rarely consider pregnancy and disability together. Women are often defined in terms of their disability and their disability overshadows their pregnancy and new role as a mother (Lipson and Rogers, 2000; Clark, 2002; Prilleltensky, 2003). This may not be the experience of all women, for some the opposite may occur; health professionals may fail to acknowledge the physical disability and may not discuss the possible additional and unique needs the women may have (McKay-Moffat and Cunningham, 2006). An unfamiliarity with the woman's disability impacts on the provision of appropriate care (Fiduccia, 2000). Welner (1999) found that the casual attitude of some health professionals towards complications that may occur can instil a lack of confidence and facilitate a state of discomfort between health professionals and the woman. Many health professionals make a conscious effort to avoid discussing the reproductive concerns and issues of women with disabilities because they are overwhelmed by their workload and unable to manage additional problems (Welner, 1999).

3.5.4.3. Lack of knowledge in health care professionals resulting in increased medicalisation of birth

As described above, women with disabilities who need to access health and maternity services must negotiate between their own self-identity as a healthy woman and the medical perception of disability. Women with physical disabilities have identified how decisions in relation to mode of delivery usually occur without consultation with them or assessment and consideration of their ability to deliver vaginally, despite their wish to do so (Lipson and Rogers, 2000; Smeltzer, 2007). Instrumental or operative birth is commonly advocated by health professionals (Lipson and Rogers, 2000; McFarlene, 2004). Physicians unfamiliar with caring for women with physical disabilities base their decisions on rigid protocols devised primarily for the larger population of women without disabilities, so the woman's birth choices may not be respected (Lipson and Rogers, 2000).

3.5.4.4. Lack of knowledge in health care professionals resulting in poor postnatal care

Bias and insensitive care also extends to the postnatal period. Health professionals lack knowledge about the necessity to refer women to allied health professionals, support services and networks. Women describe a lack of specialised and adapted instruction, for example, no referral to adaptive aids or techniques that might assist with breast-feeding and instruction on parenting skills not being specific or tailored for women with physical disabilities (Lipson and Rogers, 2000). Some health professionals focus predominantly on the physical disability and fail to consider the woman as competent (Thomas, 2001; McGuinness, 2006) and capable of becoming a parent.

3.5.5. Recent improvement in societal attitudes

Data from the first ever national survey exploring public attitudes to disability, commissioned in 2001 by the National Disability Authority presents an interesting picture of how disability is perceived and accepted in the Irish context. The study revealed how an individual's personal experience of disability impacts significantly on the establishment of their attitude toward people with disabilities (NDA, 2002). Five years later the survey was repeated and the relationship between attitudes and personal experience was identified once again. Evidence from this second survey suggests that people's attitudes towards disability are improving (NDA, 2007) but society still has a long way to go before inequalities and the social exclusion of people with disabilities are to be adequately addressed. Responding to a question on whether people with disabilities should or should not have children, the majority of respondents (84%) drawn from the general population agreed that people with physical disabilities have the right to become parents, while a similar number (87%) of respondents agreed that people with sensory impairments should have children if they chose to (NDA, 2007).

The introduction of legislation, policy and many other initiatives may all have contributed to the change of attitude evident in the second survey. The initiatives include the implementation of the National Disability Authority Act (Government of Ireland, 1999), the Equal Status Act (Government of Ireland, 2000); the European Year for People with Disabilities (Council of Europe, 2003); the Special Education Needs Act (Government of Ireland, 2004), Disability Act (Government of Ireland, 2005) and more recently, the National Disability Strategy (Department of Justice, Equality and Law Reform, 2004). Although it is important to acknowledge the change in attitudes between the 2 surveys, periodic monitoring of attitudes over time is useful in order to differentiate the transient fluctuations in attitudes from ongoing positive trends that may occur at the time any survey is completed.

3.6. Facilitators to overcome accessibility challenges for women with physical disabilities

3.6.1. General facilitating factors

The environmental challenges that exist for people with disabilities are solvable (Moore, 1997; Veltman et al, 2001) and all health care facilities should be made physically and socially accessible. The following suggestions may alleviate the many challenges encountered by women with disabilities in accessing the services. Policies and guidelines that promote access for women with disabilities should be devised, implemented and audited on a regular basis, involving women with disabilities in the development phase and auditing phases (Nzegwu, 2004). Consideration should be given to creating a specialist role to cater for the needs of women with disabilities, for example, a disability advisor (Brown, 2001). A robust complaints mechanism should be established to enable feedback from women to be heard and acted upon (Nzegwu, 2004).

3.6.2. Factors regarding location of services

Women should receive health care as near to their home as possible (Institute of Obstetricians and Gynaecologists Subgroup, 2006). Community based models of midwifery care, for example, Domino schemes, should be developed in all maternity units (Institute of Obstetricians and Gynaecologists Subgroup, 2006), which will enhance continuity of care and choice for women (Women With Disabilities Australia (WWDA), 2004; HSE, 2005) and facilitate women with disabilities, in particular, to choose their preferred model of care. All women should be provided with information about these services (WHC, 2004). Service providers should be more creative and flexible in the provision of care (Crow, 2003; RCN, 2007), to accommodate women with disabilities in a location near to their homes.

3.6.3. Facilitating transport to services

Reliable and accessible public transport to and from the provider's facilities is essential (Scheer et al, 2003). Failing that, women with disabilities should be provided with subsidised private transport as required.

3.6.4. Facilitating improvements in the physical environment

Structural and architectural barriers that prevent women with disabilities from accessing health care facilities and services should be identified and remedied. Modification of the built environment should occur and should be guided by the building legislation that addresses the issue of accessibility (Department of Environment and Local Government, 1997, 2000; NDA, 2002a). Remedial measures include the provision of a disabled parking bay close to the entrance and clearly signposted, change of the physical environment to ensure freedom of access, ramps externally and internally, wider exterior and interior doors, and wider corridors with access to all areas. All amenities should be within reach and the receptionist desk should be at appropriate level to facilitate exchange of information in a private and respectful manner (Jones and Tamari, 1997; Schopp et al, 2002; McKay-Moffat, 2007). A simple wheelchair tilting manoeuvre may avoid the need to transfer woman to tables for antenatal examination (Bar-Hava et al, 1999). Accessible bathroom facilities that facilitate ease of movement for people with mobility disabilities, with an emergency cord that extends to the floor should be situated on each unit and clearly signposted (McKay-Moffat, 2007). A designated unit/ward specifically adapted for women with disabilities may alleviate any issues in relation to accessibility when a woman with disability needs is admitted to the health care environment. Other modifications that will help to ensure access to health care include the procurement of suitable equipment and technical aids, for example, hoists, height adjustable hydraulic examination tables, and accessible baby cots.

3.6.5. Facilitators to improve service provision

Enhancing maternity care for disadvantaged groups, including women with disabilities, requires better planning and coordination of services utilising a multidisciplinary approach (Clancy and Andresen, 2002; D'Souza and Garcia, 2004; Kelsall, 1992; Carty et al, 1993; Goodman, 1994; Thomas and Curtis, 1997; Lipson and Rogers, 2000; Clark, 2002; Comhairle na nOspidéal, 2003; WWDA, 2004; D'Eath et al, 2005; Institute of Obstetricians and Gynaecologists Subgroup, 2006; McKay-Moffat and Cunningham, 2006). Establishing links and a mechanism of referral to the various support services will facilitate the sharing of knowledge amongst disciplines (Campion, 1997; Thomas and Curtis, 1997), thus enhancing standards of care and women's experiences, which should result in a higher level of satisfaction (McKay-Moffat and Cunningham, 2006).

A key Irish study commissioned by the National Disability Authority in 2005 captured the experience of people with disabilities, including persons with intellectual, physical and sensory disabilities, of the health services (D'Eath et al, 2005). Unlike respondents in other work (Piotrowski and Snell, 2007), women who participated in this study reported some positive experiences with the health services. The value of acceptance and reciprocity was demonstrated in the participants' experience of General Practitioners, with some exemplifying partnership approaches and inclusive practices (D'Eath et al, 2005).

3.7. Facilitators to improve accommodation of women with physical disabilities

3.7.1. Facilitators to overcome communicational and informational challenges

Women with physical disabilities should have access to all information (Thomas, 1998) and education about their condition (Mitton et al, 2007) in an appropriate language and format that is easily understandable. Health professionals must recognise that they are a conduit for information (Thomas, 1998; Harkin, 2001). Canadian research has indicated that culturally sensitive antenatal education classes should be provided specifically for women with physical disabilities (Conine et al, 1986; Carty et al, 1993). Pendergrass et al (2001) recommends that health service providers should use the internet to provide information and, in particular, to establish health information sites for women with disabilities.

3.8. Facilitators to improve acceptability of services for women with physical disabilities

3.8.1. Facilitators to overcome attitudinal challenges

Disability awareness and training should be an integral part of all health professionals' education and induction to services, supplemented with regular seminars (Carty et al, 1993; Goodman, 1994; Baker et al, 1997; Campion, 1997; Royal College of Midwives (RCM), 2000; Veltman et al, 2001; Schopp et al, 2002; Ubido et al, 2002; Scheer et al, 2003; Nzegwu, 2004; Underwood, 2004; Valios, 2004; WHC, 2004; WWDA, 2004; D'Eath et al, 2005; Harris, 2006; McGuinness, 2006; RCN, 2007; Smeltzer et al, 2007). In particular, health professionals could learn from women with disabilities (Smeltzer, 2007). Health professionals should embrace diversity (Crow, 2003) and recognise the importance of seeing beyond the disability (McGuinness, 2006).

3.8.2. Facilitators to increase health professionals' knowledge

All health professionals should receive periodic training on the correct and safe handling and transfer of women with a physical disability (Baker et al, 1997; Grabois et al, 1999). Such training should encourage and facilitate professionals to use women's own adaptive equipment (Carty et al, 1993). Instigating early referral systems to allied professionals, such as occupational therapists or physiotherapists (Carty et al, 1993; Thomas and Curtis, 1997; Thomas, 1998; Lipson and Rogers, 2000; WWDA, 2004; RCN, 2007), will facilitate an assessment of need. Health professionals should also enhance their knowledge of the services and supports available to women with disabilities (RCN, 2007), in order to be able to inform women as required. In order to develop their knowledge, health professionals should listen to, and learn from, women with disabilities, recognising that they are the experts in terms of their disability (Baker et al, 1997; Campion, 1997; Crow, 2003; D'Eath et al, 2005; RCN, 2007).

3.9. Summary

This chapter commenced with a definition of the term 'access to services', which has been described as having 5 components: availability, accessibility, accommodation, affordability and acceptability. Barriers reducing the accessibility of services were found to relate to the location and models of care, difficulties in transport, and moving around the physical environment. These were perhaps the most obvious barriers encountered, and led to difficulties for the women concerned. Barriers to the accommodation of women with physical disabilities centred mainly on the lack of provision of suitable health information and less so around difficulties with communication, which tended to be caused by physical mal-positioning of reception desks and staff. Barriers to the acceptability of services to women were encountered in terms of lack of knowledge and negative attitudes and behaviours from staff, which upset many women.

The facilitators to access were more difficult to ascertain from the published literature. Most factors described related to improving access to buildings and services, with some emphasis on developing ease of movement around the physical environment. Facilitators to accommodation of women with physical disabilities focussed on the provision of sensitive antenatal education classes. Facilitating acceptability of services for these women would require considerable work on developing health professionals' knowledge of, and attitudes towards, physical disability.

Chapter Four: Women with vision and hearing impairment: barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood

4.1. Introduction

Initial sections of this chapter will present the barriers to accessing services experienced by women with a vision or hearing impairment, as identified from 18 published research papers (Appendix 4, Table 4). Only 2 of these (and 5 other) papers presented facilitators to access (Appendix 4, Table 5), which are discussed in the final section. One further small section is included in this chapter, exploring the experiences of women with disabilities who are from ethnic minority groups, as the barriers are similar to those encountered by women with sensory loss.

4.2. Barriers to accessibility of services for women with a visual impairment

Kent (2002) reports that women with a visual impairment may be faced with a constant battle to maintain a sense of dignity and respect when accessing health care. One in 10 women with a vision impairment experiences, for example, some degree of difficulty in accessing and negotiating the internal environment of health care facilities (Nzegwu, 2004). Details of appointments and correspondences are usually in written format, which is inappropriate for women with a visual impairment. When availing of these services, the majority of women with a visual impairment will require orientation to the health care setting (Pierce, 2003). This should include assistance in completing registration forms, locating a seat in the waiting area, and moving or transferring to and locating the examination rooms, but very few women receive this assistance (McFarlene, 2004; Nzegwu, 2004). To overcome these challenges, many women rely on relatives and friends to accompany them to appointments (Nzegwu, 2004). Lack of orientation to the birthing and postnatal environment reduces the woman's familiarity with the area and increases her dependence on health professionals, which impinges on her ability to care confidently for her baby without constant assistance (McFarlene, 2004). Quite often signage, because of its size or format, is unhelpful so women frequently struggle with the feeling of disorientation. These challenges are further compounded by health professionals' lack of awareness of how actions or lack of them may or may not impact on the individual's perception of self (Nzegwu, 2004).

4.3. Barriers preventing accommodation of women with a visual impairment

Obtaining accessible information is a continual challenge experienced by women with a visual impairment (Commission for Healthcare Audit and Inspection, 2008). The challenges relate to the individual's level of knowledge about pregnancy, childbirth and motherhood, and their knowledge of Braille (Smeltzer, 2007). Health professionals' attitudes and a lack of awareness of individual needs compound these challenges even more (Beverley et al, 2004). The vast majority of vision-impaired women do not receive any health information advice or leaflets in an appropriate or preferred format, for example, large print, pictorial, video and/or audio format or Braille (Nzegwu, 2004), so trial-and-error learning is a common experience of many vision-impaired parents (Conley-Jung and Olkin, 2001). A recent survey showed that only 56% of the 152 trusts surveyed in England have information available that is specifically designed for visually impaired women (Commission for Healthcare Audit and Inspection, 2008).

4.4. Barriers to acceptability of services for women with a visual impairment

In her paper Deborah Kent illustrates the challenges she encountered as a blind woman during pregnancy, birthing, and early motherhood (Kent, 2002). Health professionals' and societal attitudes feature prominently. She discusses how motherhood afforded her an 'exhilarating sense of defiance' (Kent, 2002:pg. 81) against society's stereotypical misconceptions. She discusses society's negative attitudes about blind women and motherhood, and the way these attitudes become real and tangible obstacles in a blind woman's life. She recalls how health professionals after the birth of her daughter, tried to discourage the practice of rooming-in,[4] citing her incapacity to see the baby's cot and baby as the reason to separate mother and baby at such a critical time. Kent recalled painful encounters in which health professionals questioned and challenged the competence of a blind woman to mother, nurture and care for her baby. Comments were often patronising and derogatory and she felt that health professionals and others were judging her parenting skills. The author acknowledges how many a new mother lives with 'performance pressure' (Kent, 2002:pg. 85), but a visual impairment only serves to heighten the pressure as mothers constantly struggle to prove that they can successfully fulfil the requirements of their mothering role (Conley-Jung and Olkin, 2001; Kent, 2002).

4.5 Barriers to accessibility of services for women with a hearing impairment

Deaf and hard of hearing women have widely different experiences of the social world when compared to hearing women and even women with other disabilities, so accessibility to, and provision of, health care services should recognise and respect these differences. According to Steinberg, women who are deaf engage with health care services in 2 ways, as 'individuals and as a member of a minority group' (Steinberg, 2006:pg. 2530) and are likely to be subjected to layers of different and compounding inequalities. The experiences of women who are deaf when accessing health care are under-researched and services are under-developed, although some studies (Harris and Bamford, 2001; Steinberg et al, 2002; Ubido et al, 2002; Valios, 2004; Tingle and Dunmore, 2005; Steinberg, 2006) have highlighted the challenges encountered by women when accessing health care.

The most common channel of communication used by health care facilities is ineffective for women with hearing impairment. Ringing the hospital or speaking to a health professional is an impossible task for these women. Making hospital

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[4] Rooming-in is the (usually recommended) practice of leaving babies in their cots beside their mothers all day and night, while in the maternity unit. The benefits are said to be increased bonding between mother and baby although the resultant need to wake during the night to feed the baby may be seen by some women as a disadvantage.

appointments over the telephone is difficult for women so many have to go into the clinic in person or ask somebody else to make the appointment. This can be a cumbersome task if women are reliant on public transport. Kelsall (1992) found that alternative methods of communication are rarely explored. In addition to the challenges encountered in making appointments, the majority of women who are deaf have difficulty gaining access to health care facilities that operate an intercom system (House of Commons Health Committee, 2003). Waiting for appointments is, for many, a source of frustration and embarrassment (Ubido et al, 2002). The lack of a visual call system in waiting areas means that those with hearing impairment may not be aware of when their name has been called, so they either miss their cue or rely on others to tell them when it is their turn, which relegates them to a dependent role. If women lip read they may not see or recognise their name being verbalised because health professionals may ‘over-mouth’ and shout and, especially when verbalised with impatience, it becomes difficult for women who are deaf to understand what is being said. This may lead to frustration and anxiety which further impedes the woman’s ability to lip-read or sign effectively (Kelsall, 1992; Iezzoni et al, 2004). As a result women are more inclined to avoid health services and not attend for appointments, rather than deal with the embarrassment and frustration that develop from such challenges (Iezzoni et al, 2004; O’Hearn, 2006; Steinberg, 2006).

4.6 Barriers preventing accommodation of women with a hearing impairment

4.6.1. Access to health information and antenatal education classes

There is a severe deficit in the provision of formal health information for women who are deaf (Josiah, 2004). Antenatal classes may be sources of frustration and confusion for these women. Signed antenatal classes are uncommon, so this excludes a large majority of women who use sign language as their primary mode of communication. For women who lip-read, class facilitators may pose challenges by not positioning themselves in good light, words may be unclear and rushed, slide presentations may be difficult to read and if used in a darkened room the woman cannot focus on the educator's lips, so lip-reading is impossible. The use of videos with no subtitles is inappropriate and the provision of leaflets may be inappropriate due to the difficulty some women may have with comprehension (Kelsall, 1992). Background noise and chatter can be irritating and distracting and a woman may find it difficult to concentrate on lip-reading. If strategies such as group discussions are used, women with a hearing impairment may feel excluded and may choose not to participate in the discussion because of their inability to lip-read other women in the audience, their own limited diction or simply because they do not understand what is being discussed. This isolates and marginalises women with hearing impairment even further.

4.6.2. Ineffective communication between health professionals and women with hearing impairment

4.6.2.1. Introduction

Effective communication is a fundamental challenge for women with disabilities especially those with a hearing impairment (Clark, 2002; Royal National Institute for the Deaf (RNID), 2004; NDA, 2007). Deaf women can encounter enormous challenges and discriminatory practices when accessing health care (Iezzoni et al, 2004; Steinberg, 2006) but linguistic challenge is the most significant one requiring redress (Harris and Bamford, 2001). It is estimated that 50% of women with hearing impairment experience difficulty when communicating with health professionals (Ubido et al, 2002). Communicational and linguistic difficulties can occur both at a personal level, as women interface with health professionals, and at an institutional level (Steinberg, 2006). Iezzoni et al (2004) found that health professionals fail to comprehend the uniqueness of the deaf culture and its associated linguistic identity. These challenges have the potential to exclude and marginalise women who are deaf from society.

A lack of awareness and knowledge amongst health professionals of how to approach and communicate with deaf women manifests itself as a general unwillingness to communicate. Although it is deemed an important component of good care that maternity care professionals communicate adequately with women with sensory impairments (Royal College of Anaesthetists et al, 2007), health professionals often become impatient and intolerant (Kelsall, 1992; Ubido et al, 2002; Iezzoni et al, 2004; D'Eath et al, 2005; O'Hearn, 2006) when interacting with women who are deaf. These behaviours compound the issue more and the interaction and exchange of information becomes difficult. If women are not afforded the opportunity to meet with the same individual at each visit, the quality of communication is compromised. Women feel they have to explain their deafness each time (Kelsall, 1992; Ubido et al, 2002) and become frustrated at having repeatedly to develop mechanisms to facilitate communication. In addition, the extra time and privacy needed to facilitate effective communication is not always considered or accommodated (Fraser, 1999) in health care institutions.

When women attended for an appointment unaccompanied, only 1 in 10 fully understood what the health professionals were saying (Ubido et al, 2002). Many women do not acknowledge that they do not understand or comprehend what is being said and are inclined to nod and smile at health professionals rather than ask for something to be repeated (Fraser, 1999). Women feel embarrassed (Ubido et al, 2002; Iezzoni et al, 2004) and are concerned that if they ask health professionals to repeat information over and over this may be misconstrued as a cognitive impairment and their ability to become a parent will be questioned (Fraser, 1999).

4.6.2.2. Using sign language

Deaf women are not satisfied with the communication strategies adopted by health professionals (O'Hearn, 2006). Women would prefer health professionals to use several different methods of communication (Iezzoni et al, 2004; O'Hearn, 2006), which would help to increase clarity and facilitate understanding (O'Hearn, 2006). A study of 23 deaf women, in the United States found that most of the women used American Sign Language as their primary mode of communication but many would endorse the use of some methods of oral communication such as lip-reading (O'Hearn, 2006). Many health professionals consider writing and lip-reading as appropriate and effective modes of communication; however, the majority of women who are deaf prefer health professionals to communicate using sign language or a sign language interpreter (Iezzoni et al, 2004; O'Hearn, 2006). Despite this preference health professionals in the US rarely engage the services of an interpreter (O'Hearn, 2006) mainly because they fail to recognise their responsibility to do so, and many in the United States complain about the cost and inconvenience incurred (Iezzoni et al, 2004). This can result in women feeling humiliated and frustrated (Clinton, 1995). When sign language interpreters are used, health professionals do not request that the person is proficient in the use of medical sign language (Iezzoni et al, 2004) and they have a tendency to communicate with the interpreter and not the woman, so that the woman feels isolated and excluded (Kelsall, 1992; Iezzoni et al, 2004; Smeltzer, 2007).

If present during the birthing process, sign language interpreters may be asked to act as the woman's support person and to aid in physically supporting the woman (Ubido et al, 2002); this redirects their hands and so communication is lost. In the absence of a sign language interpreter many health professionals and deaf women rely on family members and/or friends to translate what is said during the interaction. This practice is inappropriate and infringes on the woman's right to confidentiality. The potential for misinterpretation is enormous. Health professionals regularly misinterpret and misunderstand the facial gestures and expressions that are an integral part of sign language. They generally perceive the gestures and expressions as aggressive and argumentative and this often results in health professionals misinterpreting the situation and avoiding the woman (Ubido et al, 2002).

4.6.2.3. Using written information

When health professionals attempt to communicate with pen and paper the writing often poses major problems. It may be illegible and medical terms are often used, so that words are incomprehensible to the lay person. For women who are pre-lingually deaf, sign language is their first language, not English, so many women may not identify with the language and the associated vocabulary being used. In addition, pre-lingual deaf women may have difficulty pronouncing, verbalising and reading English so providing information in written format is inappropriate (Ubido et al, 2002; Iezzoni et al, 2004). Many health professionals are unaware that sign language is the first language of many women who are deaf, so interactions are generally initiated and continued on the assumption that women can lip-read, or pen and paper are used to gather and relay information. The over-reliance on written communication and the concessions deaf women have to make are a source of frustration for many women (Ubido et al, 2002; Iezzoni et al, 2004). Health professionals do not consider the possibility that for some people who use sign language, the way they view and interpret the written word differs markedly from those who are not deaf. This may mean that deaf women may not fully comprehend any written information provided (Smeltzer et al, 2007) leaving open the potential for misinterpretation (Ubido et al, 2002).

4.6.2.4. Using lip-reading

Challenges are also encountered by women who use lip-reading as a mode of communication. Health professionals may be unaware that a woman may use this skill so are not conscious of the need to ensure that their lips are seen at all times. Health professionals may talk while reading from notes, turn away, have a beard or wear a mask, making it difficult for women to lip-read (Iezzoni et al, 2004). They may not position themselves in proper light so it can be difficult for the woman to visualise the lips, or words may be unclear and rushed. Distracting background noises, analgesia, exhaustion and fatigue can make it difficult for women to concentrate on lip-reading or signing.

4.7. Barriers to acceptability of services for women with a hearing impairment

4.7.1. Attitudinal challenges from health professionals

When interacting and interfacing with health professionals the majority of women with hearing impairment do not feel respected or supported (Steinberg, 2006). Similar to women with a physical disability, their deafness becomes their defining characteristic to the detriment of the perception that they are competent individuals. Health professionals tend to be paternalistic and patronising (Steinberg, 2006) and health professionals' assumptions about the woman's deafness significantly impacts on the establishment of a productive relationship (Iezzoni et al, 2004). Health professionals fail to recognise and appreciate the totality of deaf women's lives. Disrespecting the woman's intelligence, motivation and her wishes to participate in her care is a common experience when women encounter health professionals (Iezzoni et al, 2004). The lack of knowledge of health professionals about the auxiliary aids that could assist women with hearing impairment in their parenting tasks is also a huge source of frustration for many deaf women (Harris and Bamford, 2001). Many women report being offered additional prenatal anomaly screening (Stern at al, 2002; Piotrowski and Snell, 2007) and feeling pressurised to consent to such screening, or feeling guilty or selfish if they gave birth to a disabled child.

4.8. Barriers for women with disability from ethnic minority groups

There is a paucity of research in relation to the experiences of women with disabilities who are from ethnic minority groups (Pierce, 2003). The lack of information helps to sustain the challenges encountered by this population as the deficit in the provision of health care services remains unexplored and undocumented. The physical, attitudinal, communicational and informational challenges experienced by this population is similar to those discussed in relation to women with a sensory impairment; however, for this population the issue of ethnicity compounds women's experiences even more and the effects are often more profound and detrimental. Women in this population are 'exposed to multiple discriminations based on racism and disablism' (Pierce, 2003:pg. 4). Moreover, many health professionals lack awareness of and contact with minority ethnic women with disabilities (Pierce, 2003).

Similar to other women with disabilities the woman's impairment is considered as the main component of her identity, often to the determinant of other components such as gender, race and ethnicity (Shah and Priestley, 2001). Consequently, the woman's culturally different needs are overlooked and ignored, or if determined the women is treated indifferently (Shah and Priestley, 2001). Health professionals' indifference of other cultures is often portrayed as insensitivity (Shah and Priestley, 2001; Pierce, 2003), which can have a detrimental effect on the health and social well-being of women with disabilities from ethnic minorities and can marginalise them even more. The most common challenges encountered by women in this population is the lack of knowledge about available services, inadequate provision of appropriate information and linguistic and communication challenges (Pierce, 2003). Health information is not available in both the appropriate language and the appropriate format such as large print, pictorial, video and audio or Braille format (Pierce, 2003), which raises important questions around the issue of informed decision making and consent.

The communication challenges encountered by this group can be immense. Translators are necessary to facilitate effective communication but they are not always available when required. Women incur long delays while waiting for translators to arrive for an appointment and in some instances their services may not used at all. In the latter circumstance health professionals rely on family members or friends to act as interpreters. This is inappropriate and there is huge potential for information to be misinterpreted. When sign language interpreters are used, difficulties can be encountered because sign language differs in different countries so the interpreter may be unable to interpret the women's signing or the women is unable to interpret the information being signing. An awareness of cultural differences in communication styles is lacking, which also leads to misinterpretations.

4.9. Facilitators to overcome accessibility challenges for women with sensory loss

If entry to the health care facility is via an intercom system, it would be more effective to use one with a light that indicates when the door is open, or to purchase a video-entry system (RCN, 2007). The use of auxiliary aids such as telephone amplifiers, pictorial signage, audible, visual and tactile systems in waiting rooms (Clark, 2002; Kaplan, 2006) will ensure that persons with a sensory impairment can access the services when required and move around with some sense of independence. In particular, installing a flashing light/number system in all waiting areas will help women with hearing impairment identify when it is their turn to be seen by the health professional. Seats should also be strategically placed to face the receptionist so that they can signal to the woman when her name is announced. Hearing aid users should be encouraged to approach health professionals with any concerns or queries (Ubido et al, 2002).

4.10. Facilitators to overcome accommodation challenges for women with sensory loss (including those women from ethnic minority groups)

4.10.1. General facilitating factors

It has been suggested that developing facilities and interventions specifically for deaf adults would help to facilitate accessibility and women's self confidence (Jones et al, 2007). Women with sensory loss should have access to all information (Thomas, 1998) in an appropriate language and format that is easily understandable. Early in the development of the relationship between health professionals and the woman, her preferred method of communication should be ascertained and clearly documented. Consultation times should be extended in order to facilitate effective communication and the exchange of information.

Culturally sensitive antenatal education classes specifically for women with disabilities should be provided (Conine et al, 1986; Carty et al, 1993).

4.10.2. Facilitating communication with women with visual impairment

All information provided should be given in large print, audio or Braille format as appropriate (Clark, 2002; Nzegwu, 2004).

4.10.3. Facilitating communication with women with hearing impairment

To facilitate lip-reading, health professionals should face women directly, speak slowly and clearly and avoid any exaggerated facial gestures. The exchange should occur in adequate light without glare. Background noise should be reduced and professionals should avoid wearing masks (RCN, 2007).

It is reported in the literature that if a woman needs and wishes to have a sign language interpreter, then one should be arranged to be present for each planned interaction, and ‘on call’ to attend when necessary (Clark, 2002; Ubido et al, 2002; Steinberg, 2006; Trotter, 2006). Using technology such as telephone or remote/video conferencing (Jones and Gill, 1998; Underwood, 2004) may also be considered. Clark (2002) argues that health professionals should receive training in sign language to level 3 standard, which may alleviate problems encountered when a shortage of professionally trained interpreters is encountered. Incorporating and increasing the use of technology, for example, visual alert, displays, minicom and loop systems are other ways to facilitate communication (Ubido et al, 2002; Underwood, 2004; Valios, 2004; D’Eath et al, 2005).

Health professionals should form links with deaf mothers and facilitate the establishment of a peer support network which would be a vital source of support for women who are deaf (Steinberg, 2006). All information provided should be given in pictorial, written or video form with sub-titles (Nzegwu, 2004).

Information on technological aids, for example, vibrating mattresses or light alarms should be provided (Thomas, 1997).

4.10.4. Facilitating communication with women with sensory loss, who are from an ethnic minority group

Health professionals need to develop a sensitive appreciation of different cultures (Shah and Priestley, 2001; Pierce, 2003). Information about available services and health information should be provided in both the appropriate language and the appropriate format such as large print, pictorial, video and audio or Braille format (Pierce, 2003). Translators and sign language interpreters need to be from the correct ethnic background and use a sign language that is interpretable by the woman (Pierce, 2003).

4.11. Facilitators to improve acceptability of services for women with sensory loss

As discussed previously, disability awareness and training should be included in all health professionals' initial and further education (Ubido et al, 2002; Nzegwu, 2004; Harris, 2006; RCN, 2007; Smeltzer et al, 2007). Health professionals should also enhance their knowledge of the services and supports available to women with sensory loss and should listen to, and learn from, these women (RCN, 2007; Smeltzer, 2007).

4.12. Summary

Barriers to the accessibility of services focussed mainly on the difficulties of orientation to the health care setting, completing registration forms, locating a seat in the waiting area, and realising when to go into the examination room. The major area where barriers to accommodation of women with sensory loss caused most distress was in relation to communication and health education, where women with hearing impairment, in particular, were at a great disadvantage. The literature on barriers to the acceptability of services showed that women with sensory loss do not feel respected or supported and that health professionals fail to recognise and appreciate their needs.

Facilitators to improve access to the services included use of telephone amplifiers and/or pictorial signage, audible, visual and tactile systems in waiting rooms and information provided in an appropriate language and format. Extended consultation times and culturally sensitive antenatal education classes were recommended. Disability awareness and training for health professionals, particularly in speaking correctly for lip-readers, and in the use of basic sign language should be encouraged. It was also found that the employment of sign language interpreters in appropriate language is useful for women with sensory loss who are from ethnic minority groups.

Chapter Five: Women with mental health difficulties: barriers and facilitators to accessing services and professional help during pregnancy, childbirth and early motherhood

5.1. Introduction

Seeking help from professionals has many layers of difficulty attached. A review of the literature suggests that the experiences of mothers with mental health difficulties accessing services, during pregnancy, childbirth and early motherhood have received little attention in the research and in service development, so there is little basis for confidence that their needs, and those of their children, are being met. Individual narratives and research on women's experiences of mental health difficulties during pregnancy and motherhood suggest that there are a number of significant socio-cultural, professional and service issues that coalesce together, making accessing help and support a large task for a mother experiencing mental health difficulties.

Initial sections of this chapter will present the barriers to accessing services, as identified from 23 published research papers (Appendix 5, Table 6). In addition to factors under the headings of accessibility, accommodation and acceptability, this group of women were unique in having specific problems with the lack of availability and affordability of services also. Finally, facilitators to improve access are presented, although it is notable that only 9 of the published papers discussed facilitators to access, in addition to highlighting numerous barriers (Appendix 5, Table 7).

5.2. Barriers to availability of services for women with mental health difficulties

5.2.1. Links between maternity and mental health services

For women who experience perinatal mental health difficulties, rapid access to appropriate specialist services and treatment is recommended to lessen women's maternal distress and the possible negative impact on the baby (Royal College of Psychiatrists, 2002). Perinatal mental health services should be seamless; embracing a number of specialist areas, and with interdisciplinary working between midwifery, obstetrics, mental health professionals and GP. However, services to women who experience perinatal mental health difficulties are often nonexistent, disconnected, fragmented, difficult to access or inadequate in meeting the specialist needs of mothers (Miller and Finnerty, 1996), and links between maternity and mental health services are weak (Currid, 2004). Consequently, women experience suboptimal perinatal care, with their mental health issues being considered separately from their pregnancy (Miller and Finnerty, 1996). Currid (2004) is of the view that maternity staff focus on biological aspects of pre and post natal care, view pregnancy and childbirth as their domain, and fail to see that maternity care embraces a number of specialist areas.

In a recent study of 152 trusts providing obstetric or midwifery-led maternity services in England, 56% of trusts stated that they held certain antenatal clinics jointly with specialists in substance misuse, and 63% employed specialist midwives to support women who misused substances during pregnancy. Joint clinics were also held by approximately one third of trusts with mental health teams for women with a history of previous postnatal psychosis and psychiatric disorders, 19% employed specialist midwives to care for women with previous puerperal psychosis and 21% had specialist midwives to support women with a psychiatric disorder (Commission for Healthcare Audit and Inspection, 2008). However, 42% of trusts had no access to any specialist perinatal mental health service and in a small number of trusts; the maximum wait for referral of women to specialist mental health services was described as a month, or more.

5.2.2. In-patient and community services

Across Europe there are wide variations in access and use of services (Chisholm et al, 2004). Despite the recommendations that were made after the Confidential Enquiry into Maternal Deaths (Lewis, 2007) and the comprehensive National Institute of Clinical Excellence guidelines (NICE, 2007), very few existing services in England are resourced to fulfil the recommendations made. Specialist perinatal mental health services are developing in a piecemeal fashion and evidence from a survey of specialist perinatal services in 78 trusts in England highlights inadequacies in provision, specialist training and staffing (Oluwatayo and Friedman, 2005). Of the 57 trusts who responded to this survey, only 13 (23%) had evidence of providing a full range of services, ranging from inpatient units, intensive home treatments to perinatal liaison services. Twenty of the trusts (35%) had designated perinatal multidisciplinary teams, with 11 trusts reporting that they had one or more full time community nurses. Less than 10 trusts reported having the services of a psychologist or social worker, and only 2 had a full-time perinatal psychiatrist; consequently, liaison psychiatrists with a special interest in prenatal health constituted the majority of consultants involved.

In the more recent study by the Commission for Healthcare Audit and Inspection (2008), only 40 of the 152 trusts were able to provide data on the recording of mental health needs by maternity care staff. Only 29 trusts provided data on referrals of women to mental health teams, and the referral rate ranged from 0% to 7% (Commission for Healthcare Audit and Inspection, 2008). Over half (55%) reported that the current mental health status of women on booking was explored using specific questions recommended by NICE (NICE, 2007). However, only 24% of the 4,950 staff surveyed across all trusts agreed, and another 43% agreed to some extent, that there was support for women with mental health needs (Commission for Healthcare Audit and Inspection, 2008).

Despite the report of the Confidential Enquiries into Maternal Deaths (Lewis, 2005) in the United Kingdom identifying the need for women with mental health difficulties to be cared for in specialist mother and baby psychiatric units and not be separated from their baby, Oluwatayo and Friedman (2005) found that only 21 (37%) of the trusts had facilities for admissions of these mothers and their babies. Of these, one third consisted of designated beds in open wards, as opposed to designated units. In the more recent study described above (Commission for Healthcare Audit and Inspection, 2008), 95% of trusts stated that they had some access to a mother and baby unit, which, if accurate, is a remarkable improvement in these facilities in the space of 3 years.

Glangeaud-Freudenthal and Barnett (2004) in a audit of mother and baby units in different countries identified approximately 30 units in the United Kingdom, over 10 units in Australia and New Zealand, and 15 in France and Belgium. In the absence of specialised units, women with mental health difficulties are admitted to mixed sex, acute psychiatric units that are ill equipped to meet their or their baby's specialist needs.

Within Ireland, the Women's Health Council (2005:pg. 7) point out that the mental health services 'are gender-neutral at best, and skewed towards the needs of the male population at worst'. They also highlight the inadequate resourcing of maternity services to deal with postnatal depression. Although there are consultant psychiatric attachments to the 3 main Dublin maternity hospitals, and a Mental Health Liaison Midwife was appointed at The Rotunda Hospital in 2001, there are very few resources outside of the Dublin region and no Mother and Baby Units (WHC, 2005).

5.2.3. Provision of services appropriate to needs

The latest NICE guidelines recommend that the full range of therapeutic services, such as psychology, psychiatry, nursing, social work and psychotherapists, should be available to women (NICE, 2007). The lack of availability of such services to suit women's needs is, however, evident in research that explored women's preferences and experience of care. While the majority of the women (n=45) in Zittel-Palamara et al's (2008) study valued counselling, medication, support groups (in-person and online), spiritual assistance, psychiatric and psychology input, few received the care they desired. Although approximately 75% of women wanted assistance from a psychologist and 78% desired care from a social worker for their postpartum depression, less than 25% and 11% were able to access the care they required. Within Ireland, inequalities in the provision of mental health services have been reported (D'Eath et al, 2005), and the expert group on mental health stressed the need to move beyond the current biological and illness-focused mental health services to a more 'biopsychosocial model' of practice. They were of the opinion that 'the artificial separation of biological from psychological and social factors has been a formidable obstacle to a true understanding of mental health… [and resulted in] …lost opportunities for the provision of psychological and social interventions for people' (Government of Ireland, 2006:pg. 18).

5.3. Barriers to accessibility of services for women with mental health difficulties: Impact of symptoms on ability to take action

5.3.1. Inadequate recognition or denial of pregnancy

Given the high incidence of unplanned pregnancies among women with serious mental illness, some of these women may have difficulty in recognising or acknowledging that they are pregnant and consequently delay accessing prenatal advice. This may occur especially among women who have erratic menstrual cycles due to the side effects of prescribed medication or substance misuse (Hser and Niv, 2006). Although rare, women with enduring mental health difficulties, such as schizophrenia, who have previously lost custody of children, have been found to deny their pregnancy to avoid the grief associated with anticipatory custody loss (Apfel and Handel, 1993; Nicholson et al, 1998a). Such denial reduces the chances of prenatal care, and increases the risk of postnatal emotional problems including, in some cultures at least, neonaticide[5]

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[5] Neonaticide is the killing of a baby at birth, or (an extension of the definition) within the first 4 weeks of life

(Green and Manohar, 1990; Lee et al, 2006), a circumstance that could be avoided if they felt confident enough to confide in health professionals. A retrospective study of medical records in an urban academic medical centre in Cleveland over a 6-year period showed that, out of 31,475 births, 61 women had denial of pregnancy (0.19%). For 13 of the women (21%), the babies were removed from their custody prior to discharge from the hospital (Friedman et al, 2007).

5.3.2. Women's motivation to access services

Seeking help for a health problem requires a level of self-confidence and motivation. The experience of depression, with all of the resulting symptoms such as tiredness, poor self-esteem, lack of motivation, and overwhelming sense of worthlessness, guilt and despair can make accessing help extremely difficult for women, especially when services are so poorly integrated and developed. In Lau and Wong's (2008) study, Chinese women with depressive symptoms were less likely to seek help than women in the non-depressed group, suggesting that a reciprocal relationship exists between symptoms and help-seeking behaviour. In other studies, postpartum depressive symptoms, such as difficulties in motivation and self-confidence, were identified by the women as a barrier to seeking help (Zittel-Palamara et al, 2008). Borjesson (2005) also suggests that feelings of guilt, low self-esteem and hopelessness accompanying depression contribute to women's reluctance to talk about their emotional distress. Depression during pregnancy has also been associated with poor attendance at prenatal care (Mowbray et al, 1995b).

5.4. Barriers preventing accommodation of women with mental health difficulties: Access to health information

5.4.1. Women's knowledge about antenatal mental health difficulties

Another possible reason that pre and postpartum mental health difficulties, especially depression during pregnancy, go undetected is that women are not prepared for the possibility of it happening to them. The emphasis on postnatal depression, to the exclusion of other mental health difficulties, may exacerbate women’s lack of recognition during pregnancy of depression and other mental health difficulties, such as anxiety. Consequently, pregnant women may not recognise their distress as depression or anxiety, and postpartum mothers may simply attribute their distress to hormonal changes, a ‘normal’ part of the post natal period or an adjustment reaction to sleep deprivation.

5.4.2. Information provision about antenatal mental health difficulties

Childbirth educators have a key opportunity to educate women and their partners about the range of possible postnatal reactions, from baby blues to psychosis. In addition to teaching women about managing labour, educators can offer information that will help normalise postnatal emotional experience and recognise if these experiences are becoming too difficult for women to cope with by themselves, and how to seek help. However, both the lack of availability of classes and lack of attendance at such classes exacerbates the problem. Even if available, women report that they receive very little information on mental health issues during prenatal care and have little or no knowledge on how to access health or community resources if needed during the postnatal phase (Buultjens and Liamputtong, 2007).

5.4.3. Women’s knowledge about services and help available

Locating support services and obtaining information about services can be another major barrier to women accessing support. Lack of knowledge on how to seek help or what service to access was identified as a barrier to receiving care by Zittel-Palamara et al (2008). Almost 16% of the 45 women in this study reported not knowing who to speak to, with an equivalent number seeking help but unable to locate any assistance. Lack of knowledge on services available and the skill set necessary to access service are likely to be more pronounced in some groups of women, such as recent immigrant women (Teng et al, 2007), homeless women, and women with substance abuse or other severe mental health difficulties.

5.4.4. Lack of fluency in English leading to lack of knowledge of services

In Ireland, a study of refugee and asylum-seeking women found that they may be at increased risk of depression in the postnatal period due to the added stress of their situation (Kennedy and Murphy-Lawless, 2002). Accessing services requires a level of language proficiency, which is a major issue for some immigrant women. Health care professionals in Teng et al’s (2007) study were of the view that lack of fluency in English was a major barrier for immigrant women accessing information on mental health service provision. Language was also reported to be a barrier in providing care. Although translators were helpful when women entered the service, the professionals were of the view that they were not ideal as, in the presence of a third person, important discussions on personal issues, such as mental health difficulties, were often limited in depth.

5.5. Barriers preventing accommodation of women with mental health difficulties: Assessment and screening practices

5.5.1. Assessment practices

Routine prenatal and postnatal visits to health professionals such as midwives, public health nurses, paediatricians, or general practitioners provide good opportunities for these health care professionals to establish therapeutic rapport and explore with women their emotional state and experiences of emotional distress. Although pre and post natal mental health difficulties are prevalent they frequently go unrecognised and untreated by health care professionals (Wiley et al, 2004; Sleath et al, 2007).

Kelly and colleagues (2001) found, within a large group of pregnant women they studied (n=186), 38% met the criteria for a mental illness or substance abuse disorder; however, only 43% of these women had symptoms recorded in their charts, 18% had a formal diagnosis, and one third (33%) received any kind of intervention or treatment. Similarly, Chaudron et al (2005) found that 28% (61) of the Hispanic women (n=218) in his study were of the view that they needed help with postpartum depression, however, over 50% (32) reported that their primary doctor or health professional did not speak to them about their feelings. Five of the 6 women in Edwards and Timmons's (2005) study (83%) reported delays in receiving help, as health care professionals (midwives, GP, health visitor) were slow in recognising their distress as postnatal depression or discounted it as a 'normal' part of post birth experience.

5.5.2. Lack of knowledge, time and awareness in maternity care professionals

Lack of education and awareness amongst maternal healthcare professionals of the significance of known risk factors for mental illness is considered a significant factor in the under-assessment (Lewis, 2007). Others suggest that the problem resides with the biomedical model of communication, which affords professionals little opportunity for psychosocial or emotional discussion (Roter et al, 1999). Under-diagnosis has also been attributed to a failure and reluctance on behalf of professionals to ask women about feelings of depression or hopelessness (Marcus et al, 2003; Sleath et al, 2007). Although obstetricians and midwives (n=20) in Mancini et al's (2007) study in New Mexico (Mancini et al, 2007:pg. 433), were positive about using the Postpartum Depression Screening Scale, they reported feeling uncomfortable discussing depression and expressed concern about 'opening up a can of worms', with which they felt inadequate to deal. Of the 389 paediatricians who returned the survey questionnaire, in Wiley et al's (2004) study in the United States, only 31% expressed confidence in their ability to recognise postpartum depression, with only 7% reporting that they were familiar with screening assessment tools. Not surprisingly, 51% underestimated the incidence of postnatal depression, with 49% reporting receiving little or no education on the topic. Lack of time (69%), lack of office space (57%), lack of referral recourses (43%), and lack of effective treatments (5%) were considered as barriers to screening in practice.

The tendency, internationally, to focus on maternal depression, with the term postnatal depression being used as an all-embracing category for perinatal mental health difficulties (Austin and Priest, 2004), also results in other mental health difficulties such as prenatal depression, anxiety, panic disorder, psychosis, and women with severe mental health difficulties and substance misuse being overlooked (WHO, 2000; Austin and Priest, 2004).

5.5.3. Screening practices

As an outcome of the Inquiry into Maternal Deaths and other reports, the National Institute for Health and Clinical Excellence made a number of recommendations to the National Health Service (NHS) on pre and postnatal care for women including the key priorities of ‘prediction and detection’ of postnatal mental illness (NICE, 2007:pg. 4). In addition, the Council Report of the Royal College of Psychiatrists into perinatal mental health services stated that perinatal mental health care should incorporate risk assessment and early identification of illness (Royal College of Psychiatrists, 2002). However, in situations where health care professionals screen women, it is clear that they lack the skills to explore with women their emotional needs in a sensitive manner (Shakespeare et al, 2003). There has been much criticism about the way in which the NICE guidelines are being implemented, following complaints from mothers. The Association for Improvements in Maternity Services (AIMS) reported that women were already complaining about the way that healthcare staff questioned them about their psychiatric histories (Robinson, 2007). Despite recommendations for sensitivity in official guidelines from NICE, women report feeling hassled, labelled and stigmatised. As a result their trust in maternity care is being damaged. AIMS asks whether the drive to record all past periods of mental illness will have a positive impact on risk and improve care, or whether the process will increase negative outcomes for women. The evidence from AIMS suggests that this has the potential to increase stigma and increase the risk that women’s complaints about poor quality care will be rejected. Those who confide their distress to health visitors frequently regret doing so, and warn their friends to be careful about telling the truth (Robinson, 2007).

Shakespeare et al (2003) interviewed 39 postnatal women, attending 22 community GP practices in Oxford, to explore the acceptability of postnatal screening with the Edinburgh Postnatal Depression Scale (EPDS). Over half of the women (21) found screening unacceptable, felt it was an intrusion and were fearful of the consequence for both themselves and the baby. Consequently, they reported deliberately giving false, and positive, responses. Women were of the view that, because of lack of time, feedback and privacy, the baby clinic was an inappropriate place to assess them in any case. The women in this study also expressed a clear desire for talking about what they were feeling in an open, non-judgemental, supportive environment, as opposed to a question and answer session, which focused on ticking boxes.

Robinson (2007) suggests that identifying women at risk may be fine, if the supportive care that women need follows. However, she is of the view that the ‘child protection mania’ which currently exists (to ‘cover people’s backs’), results in health care professionals referring women to social services and social workers, who may be ignorant about maternity care, postnatal mental illness and care of the newborn. This raises questions about the appropriateness of routine screening for perinatal mental health difficulties, as what could have been a positive initiative, in terms of identifying women in need of supportive care, is in fact becoming a barrier to disclosure.

5.6. Barriers to acceptability of services for women with mental health difficulties: Stigma and shame

5.6.1. Stigmatisation and discrimination

There is extensive research that suggests that people who experience mental health difficulties are stigmatised and suffer discrimination and rejection in relation to employment, housing and health insurance. People who fear the stigma of mental illness often forgo treatment, in an attempt to avoid the label. In the context of women who experience mental illness associated with childbirth the evidence base is sparse. However, what is available suggests that the perceived stigma associated with mental illness is a reality, creating and exacerbating problems for women accessing help and support (Shakespeare et al, 2003; Edwards and Timmons, 2005; Jesse et al, 2008). Women in Jesse et al’s study (2008:pg. 9) feared that if they asked for help they would be labelled 'crazy', which would result in 'discrimination' and 'stigmatisation', should their illness become known. Although the 6 women admitted to a mother and baby unit in Edwards and Timmons's (2005) study were positive about their treatment and diagnosis, they were concerned about stigma and discrimination from organisations if, in the future, they had to disclose their illness on emigration or life assurance forms.

5.6.2. Labelling and shame in a multi-cultural population

Within cultures where mental health difficulties are equated with moral weakness, revealing mental distress is likely to evoke criticism and blame as opposed to empathy and understanding. The Black Caribbean women (n=12) in a United Kingdom study on perinatal depression (Edge and Rogers, 2005; Edge, 2006), suggest that cultural imperatives to be stoic, by minimising and denying psychological distress, is a barrier to Black Caribbean women seeking help with pre and post natal depression. For these women their sense of self was bound up in their ability, as Black women, to cope with adversity. Consequently, they resisted the label of depression, as in one woman's words 'you live to your label' (Edge and Rogers, 2005:pg. 21). Being labelled 'depressed' would result in others regarding them as less competent, threatening their self-concept and social status. The women also suggested that talking about 'your business' outside the family was a cultural taboo and would be perceived as being 'disloyal' to the family. They expressed doubts about the professionalism of counsellors and were of the view that counselling was unlikely to be helpful, due to the unavailability of Black Caribbean counsellors. Hence, they tended to draw on spiritual sources for emotional support as opposed to professional intervention.

Lau and Wong (2008) explored the impact of 'maintaining face' on Chinese women's willingness to seek help for postnatal depressive illness. Findings from this study suggest that Chinese women also prefer to seek help from informal sources, such as family members and friends, as opposed to professionals. In addition, women with a high concern for 'maintaining face' were 1.36 times less likely to seek help during the postnatal period, suggesting that cultural and social issues may result in women minimising or denying their distress. Although an important source of psychological support, the propensity to draw on informal sources of support may have implications for women from other cultures, affecting their willingness to seek help from professionals for psychological problems.

Teng et al (2007) interviewed 16 health care workers in Canada, regarding their experiences of providing care to recent immigrant women with postpartum depression. Participants in this study were of the view that cultural conflicts acted as major barriers. The lack of cultural recognition, especially within non-Western cultures, of postpartum depression as a ‘medical problem’ requiring intervention, the stigma and shame associated with a ‘label’ of mental illness, and the cultural imperative that family issues are not discussed outside the home, may result in many women denying their distress, for fear of being alienated or bringing shame on themselves and their family. In addition, a lack of spousal support and validation of the need to seek help was also viewed as a barrier.

5.7. Barriers to acceptability of services for women with mental health difficulties: Fear of being judged a ‘bad’ mother

5.7.1. Society’s views of mothers with mental health difficulties

Montgomery (2005) asserts that women with mental health difficulties are viewed as the wrong women giving birth in the wrong circumstances. Consequently, a significant barrier to women disclosing their distress is a fear of being judged as a ‘bad’ or ‘poor’ mother; this fear has been found to undermine women’s willingness to disclose to friends, families and professionals, which in turn leads to self-exclusion, withdrawal, decreased social networks, and reducing emotional support (Edhborg et al, 2005; Edwards and Timmons, 2005; Davies and Allen, 2007; Jesse et al, 2008).

Women who have experienced a mental health difficulty before pregnancy report being victims of stigma and negative societal attitudes from friends, family and health professionals, even before they get pregnant. They are aware that the very idea of them displaying the normal desire to bear children is perceived as selfish, with an automatic assumption that they will not be 'stable enough to function as a mother' (Perkins, 2003:pg. 157). Consequently, these women automatically encounter the medical discourse of 'relapse risk' from both family and professionals. Women are strongly advised that a worsening or relapse of 'illness' must be avoided at all costs and are continuously advised not to get pregnant, for fear of a recurrence of their illness (Nicholson et al, 1998a), with others being made to feel that getting pregnant and remaining healthy is merely a 'pipe dream' (Perkins, 2003:pg. 157). Once pregnant, women report experiencing reactions including disapproval, ambivalence and anger (Blanch et al, 1994; Mowbray et al, 1995a). Consequently, the fear of negative reactions acts as a powerful barrier to these women seeking help and support, and may result in women delaying accessing prenatal care.

5.7.2. Family's views of mothers with mental health difficulties

Family members can be a powerful source of support to women, or a source of tension and conflict. Women report that family members who do not understand their mental health difficulties are angry, resentful and blame them for problems that arise with children. In some cases family members, cast the mother in a 'sick role', undermining the women's efforts to parent or recover, by making decisions about children without consulting or considering the mother's wishes (Nicholson et al, 1998c). The long term consequence of this behaviour frequently result in women internalising societal and family assumptions about incapability and incompetence (Fox, 2004; Schen, 2005). As a consequence, mothers are less likely to seek help when needed from family and report difficulty trusting their own assessments of their children's needs, their ability to meet them and the confidence to advocate for themselves or their children (Mowbray et al, 1995a; Nicholson et al, 1998b). In addition, if women were admitted to in-patient units, these were seen as inappropriate places for children to visit, due to the lack of facilities for children, such as family rooms separate from wards (Nicholson et al, 1998a; Diaz-Canjela and Johnson, 2004).

This often prevented mothers from maintaining contact with their children during an admission, resulting in further difficulties in relationships.

5.7.3. Women's reluctance to admit to mental health difficulties

The conflict between what society constructs as 'competent' 'good' and 'nurturing' mothers, and women's experiences of emotional emptiness, distress and inability to care for a new born, leave women feeling they have no one to turn to. Women who disrupt the myth of the 'ideal mother' or who do not feel overwhelming joy and love for their newborn infant, find motherhood tiring and stressful, and continually report feelings of inadequacy, stigma and shame (Nicholson et al, 1998b; Diaz-Canjela and Johnson, 2004; Edhborg et al, 2005; Buultjens and Liamputtong, 2007). Women are of the view that both the public and professionals start from the assumption that women with mental health difficulties are unlikely to be adequate mothers, making it extremely difficult for women to seek help voluntarily (Diaz-Canjela and Johnson, 2004).

Although mothers would like to consider health care professionals as a source of support, they continually report a reluctance to admit to any feeling of stress or depression. To acknowledge mental health difficulties is akin to admitting failure as a mother. In many cases, women felt they had to guard against health professionals making moral judgments about them (Montgomery et al, 2006; Davies and Allen, 2007) and feared being thought of as 'unable to take care of the kids' (Heneghan et al, 2004:pg. 464). Mothers without a diagnosis of a mental health difficulty, attending community and hospital paediatric practices in the U.S.A. repeatedly described a fear that the paediatrician would interpret their request for help as a threat to their child's safety and, as a consequence, would refer them to a child protection agency. Mothers in lower socioeconomic groups were particularly fearful of social work interventions, because of a belief that the primary function of the social worker was to remove the child from the home as opposed to acting as a resource for help and support (Heneghan et al, 2004).

5.7.4. Women's fears of being judged 'an incompetent mother'

Mental illness is the antithesis to the stereotypical mother, falling as it does outside the romantic ideology of the 'ideal' mother (Montgomery et al, 2006). Western culture asserts that all 'normal' women feel a strong maternal instinct, want to have babies, and that birth and motherhood is an immensely joyous, blissful and happy occasion. Ugarriza (2004) points out that the inability to experience joy at being a mother is often a source of community scorn and individual shame. In addition, mothers who experience mental health difficulties are often portrayed as unable to care for their children, dangerous, violent and dislikeable (Krumm and Becker, 2006). Media representation plays an important role in perpetuating the perception of women with mental health difficulties as incompetent mothers. Within the media, the representations of mothers with mental health difficulties as 'mad' (Apfel and Handel, 1993) 'bad' (Swigart, 1991) or 'toxic' (Oates, 1997) contributes to women being viewed as a homogonous group of 'defective parents', requiring constant and sustained monitoring. Such derogatory terms also highlight the perceived differences that exist between mothers with a diagnosis of mental illness and mothers without.

This fear of being perceived as an incompetent mother was a consistent theme within studies of women with mental health difficulties, such as postnatal depression (Ugarriza, 2002; Shakespeare et al, 2003; Ugarriza, 2004; Edwards and Timmons, 2005) and was even more pronounced within studies of women with enduring mental health difficulties (Nicholson et al, 1998c; Perkins, 2003; Montgomery, 2005; Davies and Allen, 2007). Other women reported immense shame about experiencing negative feelings towards their baby and wanting time for themselves. The women (n=22) in Edhborg's study also spoke of the immense pressure they experienced to breastfeed and the deep sense of being a 'bad mother', when their struggle with depression resulted in them stopping breast-feeding (Edhborg et al, 2005).

5.8. Barriers to acceptability of services for women with mental health difficulties: Fear of loss of custody

5.8.1. Feeling the need to prove themselves

Women reported constantly feeling under pressure to prove their mothering competence and were very reluctant to reveal a mental health difficulty or seek help with parenting for fear of allegations of poor mothering practice, which could result in loss of custody of, or access to, children (Hendrick and Daly, 2000; Montgomery et al, 2006; Davies and Allen, 2007). While some mothers with enduring mental health difficulties may have difficulties, it is possible, if provided with adequate resources, for many such women to care successfully for their children (Mullick et al, 2001). The literature provides evidence of custody loss rates of between 38% and 89% (Mowbray et al, 1995b; Cogan, 1998; Joseph et al, 1999; Sands et al, 2004). Hollingsworth (2004:pg. 199) asserts that a diagnosis of persistent mental illness (schizophrenia, schizoaffective disorder, bipolar disorder with or without psychosis, and major depression with or without psychosis) is increasingly being used to ‘fast track’ the termination of parents’ right to the custody of their children.

5.8.2. Fear of services

Viewing services as a source of power over their lives, as opposed to a source of help and support, appears to be a major barrier to women’s willingness to access services and help. Fearing the power of agencies to take children into care constitutes one of the most serious barriers to women being open about their distress. Throughout the research women spoke of the risks of admitting the need for mental health care, as they perceived that this would give professionals the idea that they were not coping adequately and were ‘unfit’ mothers. In the current context of mandatory reporting, which requires health care professionals to report any concerns regarding child abuse, this fear is increasing.

Anderson et al (2006) conducted interviews with 127 low income mothers in Australia and reported that fear of custody loss resulted in a major reluctance among these women to accessing help from mental health professionals. Seventeen of the 22 women (77%) in Diaz-Canjela and Johnson's (2004) study also reported a reluctance to initiate any discussion with health or childcare services on their struggles as a mother, for fear of loss of custody. Fears around custody loss were especially acute for women who had previously lost custody of a child, as they lacked trust in the health professionals, especially if they had a past role in their loss. Montgomery et al (2006) studied the mothering experiences of 20 women with enduring mental health difficulties in Canada. The women in this study described how seeking help or acknowledging the need to take medication or agree to a hospital admission was a precarious balance between risks and benefits. An admission to an inpatient service could offer time for healing, rest and recovery; on the other hand it meant being away from home, having others care for children, and increasing the risk of 'having the kids taken away from you' (Montgomery et al, 2006:pg. 25). Hser and Niv (2006) highlight the multiple fears experienced by pregnant women with substance abuse problems. Not only does the fear of loss of custody of children act as a barrier to prenatal services, but these women also have to contend with the fear of criminal action and the stigma associated with substance abuse.

5.8.3. Trust in health professionals

Effective and empathetic communication is a core aspect of quality health service delivery, and is a significant issue in building trust with women who experience mental health difficulties. If women experience sensitive, trusting, empathetic relationships with health professionals they are more likely to disclose their distress. However, lack of trust of health care providers was one of the most frequently cited barriers to seeking help by the 30 women in Jesse et al's (2008) study. Nineteen (63%) of the women in this study were of the view that health care professionals were not to be trusted with information and were concerned about confidentiality. The lack of trust was more pronounced among African American women than Caucasian women. Suspicion around the trustworthiness and professionalism of counsellors was also an issue for Black

Caribbean women (Edge and Rogers, 2005), suggesting that there are racial disparities in barriers. Women in these studies were of the view that simply telling women that information is confidential is not sufficient, health care professionals need to build rapport with women, by demonstrating care and empathy. The need to provide culturally sensitive counselling, by utilising counsellors for different racial backgrounds, and acknowledging the centrality of spiritual support in some women's lives was also emphasised.

5.9. Barriers to acceptability of services for women with mental health difficulties: Conflict and fears over taking medication

5.9.1. Fear of addiction

For many women who experience mental distress, prescribed medication in the form of anti-depressants and or anti-psychotics form part of their treatment regime. The fear of being prescribed medication was a significant barrier to accessing services for the Black Caribbean women in Edge (2006) and Edge and Rogers's (2005) study. Women believed that if they attended a GP, anti-depressant medication would be the only treatment offered, leading to a downward spiral of addiction, increased medication and eventually a serious mental illness. This fear stemmed from previous negative experiences with health care professionals and perceptions that black people are discriminated against and subjected to unequal and inappropriate treatments by health professionals. Evidence from research in other areas of mental health suggests that that these fears are well founded. It is estimated that women are twice as likely to be prescribed psychotropic drugs as men, and less likely to be referred for specialist mental health care (WHC, 2005). In addition, black people are more likely than white people to be hospitalised through compulsory order, to be treated in a more coercive manner, and to receive higher levels of physical interventions, such as electro-convulsive therapy and drugs (Pilgrim and Rodgers, 1999).

5.9.2. Fear of effect of medications on the fetus or baby

Many psychotropic drugs, such as mood stabilisers can be a teratogenic risk to the fetus. The NICE (2007) guidelines emphasise the need to discuss with women the risks associated with becoming pregnant while on medication and the risk associated with stopping medication abruptly or in a controlled manner. Despite this the evidence suggests that women are not informed about their medications and often struggle alone with the dilemma of stopping medication and risking their own mental health, or continuing the medication and worrying about exposing the fetus or baby to harmful effects (Thomas, 1997; Chernomas et al, 2000). Einearson et al (2001), in their Canadian study, found that of the 36 women involved, 34 (94%) had discontinued psychiatric medication abruptly for fear of birth defects and harming their baby. As a consequence, many of the women suffered both physical and psychological adverse effects, including suicidal thoughts. In the majority of cases the women stopped their medication on the advice of a doctor (family physician or psychiatrist), who in their haste to ensure a ‘drug free pregnancy’ may not have considered fully the consequences of their actions. Conflict over taking anti-depressant medication and breast-feeding was also an issue for women, postnatally. Women reported fearing transmitting the medication to the baby during breast-feeding or fearing that medication would disrupt the breast-feeding experience (Ugarriza, 2002). Consequently, some of the women in Ugarriza’s (2002:pg. 232) study stopped taking medication because they did not want to ‘fail’ at breast-feeding, perceiving themselves to have already failed the test for being a ‘good mother’.

5.9.3. Fears of impaired ability to care for their children

Women also expressed concern about having to be maintained on medication to prevent relapse. The women in Montgomery et al’s (2006) study spoke of the medication as simply ‘masking’ symptoms, without having any appreciable effect on their ‘suffering’. Women in 2 other studies (Chernomas et al, 2000; Diaz-Canjela and Johnson, 2004) described how the medication slowed them down, reduced their concentration and impaired their ability to look after their children. Fatigue also prevented them from attending to their own appearance and personal grooming. Consequently, some women made decisions to forgo medication that was slowing them down so that they could parent and breastfeed (Nicholson et al, 1998c; Brunette and Dean, 2002). Although medication may be necessary in the acute phase of illness, the over-reliance on and imposition of the biomedical solutions in the treatment and prevention of relapse may increase women's reluctance to access services and/or encourage them to disengage from services prematurely.

5.10. Barriers to affordability of services for women with mental health difficulties

For mothers with low income and inadequate transportation, an inability to pay travel costs and childcare can be another barrier and added stress (Anderson et al, 2006). Difficult getting transport to and from appointments and not being able to afford a babysitter was also highlighted in Teng et al's (2007) study on immigrant mothers. The lack of crèche facilities and the inappropriateness of some mental health environments for children were seen as major barriers to engaging with services as women were unable to bring their children to their consultation (Nicholson et al, 1998a; Diaz-Canjela and Johnson, 2004). These barriers are exacerbated among mothers with severe mental health difficulties, as they are, typically, not just in receipt of low income, but in addition are parenting alone. Lack of health insurance has also been cited as a barrier to accessing services (Sobey, 2002). Thus the financial burden of accessing support cannot be underestimated, especially for low income, unwaged or recently immigrant women. A recent study in England found that 70% of the 152 trusts surveyed said they would provide home antenatal or postnatal visits for women with mental health needs (Commission for Healthcare Audit and Inspection, 2008), which would be very helpful.

5.11. Facilitators to overcome availability challenges for women with mental health difficulties

Only 10 published papers presented facilitators to access, in addition to highlighting numerous barriers. The literature provided very little in the way of suggestions to improve the availability of services, except possibly the exhortation to close the gap between policy, aspiration and service provision and to provide training and education of health professionals (Shakespeare et al, 2003), which might improve communication between professionals in maternity services and those in mental health care. The introduction of telesupport or web-based support groups (Ugarriza, 2002) might also increase the care provided in the community, albeit through lay involvement rather than through health service funded initiatives. The suggestion of providing designated perinatal multidisciplinary teams in the community (Oluwatayo and Friedman, 2005) would make a significant difference to women suffering mental health difficulties in pregnancy or the postnatal period. Assistance from psychologists and social workers (Zittel-Palamara et al, 2008) would also assist women with postpartum depression.

For women who experience postnatal mental health difficulties, rapid access to appropriate specialist services and treatment is recommended to lessen their distress and the possible negative impact on their babies (Royal College of Psychiatrists, 2002). The report of the Confidential Enquiries into Maternal Deaths (Lewis, 2007) identified the need for women to be cared for in specialist mother and baby psychiatric units and not separated from their baby. However, specialist mother and baby units are few and far between in the United Kingdom (Robinson, 2005) and nonexistent in Ireland (NWCI and NDA, 2005). Consequently, women are admitted to mixed sex, acute psychiatric units that are ill equipped to meet their or their babies', special needs.

5.12. Facilitators to overcome accessibility challenges for women with mental health difficulties

Very little work has been carried out to identify facilitators in this area and, given the negative effects of a mental health condition; it is hard for many of these women to motivate themselves to access services, especially if they are fragmented or nonexistent. The development of greater trust between health professionals and the women presenting at services is, however, one option that is likely to facilitate increased attendance (Jesse et al, 2008).

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5.13. Facilitators to improve accommodation of women with mental health difficulties

The main suggestions provided by the literature were to provide education for women about postnatal illness and the services available to them (Buultjens and Liamputtong, 2007) and to provide support groups for mothers (Ugarriza, 2002; Diaz-Caneja and Johnson, 2004). Certainly, meeting other women with similar experiences was found to be a positive experience in one small study in the United Kingdom (Edwards and Timmons, 2005).

5.14. Facilitators to improve acceptability of services for women with mental health difficulties

This was the largest section, with the most barriers described, yet there is little literature presenting suggestions of how to facilitate an improvement in acceptability of services for these women. Many of the barriers stemmed from society's and the families' attitudes to mental health, which would be hard to change. Family meetings (Diaz-Caneja and Johnson, 2004) may assist in developing understanding and acceptance among relatives, which may in turn help women to come to terms with their situation.

Training and education of health professionals (Shakespeare et al, 2003) may help to change attitudes and foster greater trust between health professionals and women attending their services (Jesse et al, 2008). Continuity of care (Heneghan et al, 2004) has also been shown to increase the trust felt by women and is recommended.

In the few studies located that asked women what type of help and support they would benefit from, all were looking for supportive partnerships with professionals. Women wanted to be treated with respect, and have their strength acknowledged. The need for professionals to see mothers as not just an 'illness', but as people living and surviving often in difficult and challenging personal and social circumstances, was emphasised. Women expressed a desire for more family meetings, help in communicating with their children, especially about their mental illness. In addition parenting skills training, occasional respite services, and early intervention with ongoing support were highlighted. The value of peer support was recognised by women who requested opportunities to meet other mothers in a group context to share experiences, and activities for children to meet other children in similar situations (Nicholson and Henry, 2003; Diaz-Canjela and Johnson, 2004). In addition, there is some suggestion that counselling services are more acceptable to most women than drugs, and non-national women prefer to have access to counsellors from their own cultural background (Edge and Rogers, 2005; Edge, 2006).

5.15. Facilitators to improve affordability of services for women with mental health difficulties

Again, there were few suggestions put forward, but one paper recommended providing childcare facilities at clinics (Ugarriza, 2004) to decrease the cost of attending for visits, which might increase attendance. Providing practical help with mothering (Diaz-Caneja and Johnson, 2004) would also be beneficial.

5.16. Summary

Women with mental health difficulties appear to suffer far more barriers to accessing services than do women with other disabilities. This may be solely because the experiences of women with mental health difficulties are better documented; however, the availability of appropriate care is certainly less and there are poor links between maternity and mental health services. Due to the women’s mental state, they may lack motivation to attend clinics or they may even, rarely, deny the pregnancy totally, which can lead to postnatal emotional problems.

Many women are ignorant of the existence of antenatal mental health difficulties and have only a slight knowledge of postnatal mental disorders. They lack knowledge of the services available to them and, due to their illness, may be reluctant to seek help. As screening practices in maternity settings are uniformly poor, and maternity care professionals are not very knowledgeable about mental health issues, many women will not have a timely diagnosis and referral made.

Even when diagnosed, many women are afraid to admit to their illness, due to society’s, and their family’s, stigmatisation of mental health disorders. This delays help-seeking actions and prolongs their illness. In addition, women fear being judged ‘a bad mother’ and, in particular, are afraid that they will lose custody of their child. Because of this, they do not trust health care providers and feel that they are continually having to prove themselves to the authorities. Other barriers stem from a reluctance to take medication, fearing that it will cause addiction, affect the fetus or baby while breast-feeding, or impair their ability to care for their children. Finally, these women tend to be from low income families and costs of childcare and transport may prevent them from accessing health care services.

Few facilitators to improve access to services were mentioned in the literature, but those that were included the provision of childcare facilities, education of health professionals, the introduction of support groups and the provision of designated perinatal multidisciplinary teams in the community. Better communication and continuity of care from health professionals could assist in developing more trust with their clients. Family meetings are recommended to assist in developing understanding and acceptance among relatives, and counselling services are more acceptable to most women than drugs.

This chapter has demonstrated clearly that there are many deficiencies in the care provided for women with mental health difficulties in pregnancy, childbirth and early motherhood. More research on what measures would provide effective support would be valuable.

Chapter Six: Women with intellectual disability: barriers to accessing services and professional help during pregnancy, childbirth and early motherhood

6.1. Introduction

The literature concerning women with intellectual disabilities and their experiences of pregnancy, childbirth and early motherhood was not extensive. Initial sections of this chapter will present the barriers for these women to accessing services, as identified from 25 published research papers (Appendix 6, Table 8). No appreciable amount of literature was found on any of the barriers except acceptability of services. It is not known, but it is unlikely that there are specific services available for women who have intellectual disabilities and are pregnant. The final section describes facilitators that were noted in only 1 paper (Appendix 6, Table 9).

6.2. Barriers to acceptability of services for women with intellectual disabilities

6.2.1. Society's attitudes to women with intellectual disabilities becoming pregnant

Stehlik (2001) traces the history of the development of negative attitudes towards the sexual and reproductive capability of women with intellectual disabilities. These negative attitudes, she argues, continue today, with prevention of conception as the ultimate aim, through the employment of involuntary sterilisation and non-consensual contraception. Priestly (2000) argues that the infantilisation of women with intellectual disability allowed their reproductive health to be ignored, with no impetus to carry out breast examinations and cervical smear testing or to maintain menstrual care. The existence of these disparities has only in recent years come to light and is now becoming a focus of care (Ditchfield and Burns, 2004; Rodgers and Lipscombe, 2005; Rodgers et al, 2006). A review of the literature on the sexual health of women with intellectual disabilities reveals little research into their pregnancy or maternity-related healthcare needs, most referring to the need for improved breast and cervical smear screening (Ager and Littler, 1998; Barr et al, 1999; Broughton and Thomson, 2000; Biswas et al, 2005; Lehmann, 2005) and for family planning education/sex education (Carr, 1995; Lehmann, 2005; Drummond, 2006). Sheerin (1998b) and others (McConnell et al, 2003; Kohen, 2004), in recognising this shortfall, call for the instigation of improved antenatal and maternity services for women with intellectual disabilities.

Studies have found frontline caring staff and parents to have conservative and protective perspectives regarding the sexuality of women with intellectual disability (Cuskelly and Bride, 2004; Drummond, 2006). Such women are often considered unable to make rational informed choices about pregnancy and motherhood, and are at greater risk to coercive sterilisation or forced contraception (Tilley, 1998; NDA, 2007). This protectionism has impeded the potential of persons with intellectual disability to make decisions about their sexuality, including reproductive health, and to self-advocate, and is evident in Simpson et al's study into the feelings, attitudes and experiences of people with ID regarding sex and sexuality. This study employed a varied sample of 500 people with and without intellectual disabilities (Simpson et al, 2006). The Irish law for the 'protection of mentally impaired persons' effectively criminalises sexual intercourse with persons who have intellectual disability (Government of Ireland, 1993). The occurrence, therefore, of a pregnancy among the intellectually disabled population is potentially the result of a criminal act, and services/families may be discouraged from bringing this to widespread attention. Such reticence may delay the openness to discussing and willingness to address the healthcare needs of women with intellectual disabilities during pregnancy, childbirth or early motherhood.

6.2.2. Society's attitudes to women with intellectual disabilities caring for their children: the presumption of parental inadequacy

The qualitative works of Booth and Booth (1993, 1994; 1995; 2002; 2003 and 2006) have revealed the anguish and grief of parents with intellectual disability who have had their children removed from their care. Whereas the levels of disability are not identified in these papers, it is likely, from the descriptions, that the participants had mild intellectual disabilities. Others, notably Tymchuk (1985), Budd and Greenspan (1985) and Tymchuk et al (1988) have explored the ability of parents with mild levels of intellectual disability to learn how to parent adequately, through decision-making training. Perkins et al (2002) and Ditchfield and Burns (2004) argue that society continues to focus on the risk to and the outcomes for the children of parents with intellectual disabilities, with no clear concern for the risks to the health and wellbeing of the parents, and, more particularly, to the mothers.

A number of authors (Kroese et al, 2002; Llewellyn and McConnell, 2002; McConnell et al, 2003; Aunos et al, 2008) have explored the issue of support networks for pregnant women and mothers with intellectual disability, noting that, in the absence of such supports, such women are more likely to experience stress and poor health. The only study located that was focussed on the outcomes of pregnancy in women with intellectual disability found increased rates of pre-eclampsia, low birthweights and increased admission of resulting babies to neonatal intensive care (McConnell et al, 2003). This important study calls for further research to explore the reasons for such adverse outcomes.

6.3. Facilitators to improve access to services for women with intellectual disabilities

The recent study of 152 trusts providing obstetric or midwifery-led maternity services in England showed that 58% of trusts in England have antenatal and postnatal information available in a specific form for women with learning difficulties (Commission for Healthcare Audit and Inspection, 2008). In making the case for improved sexual health and maternity services for women with intellectual disabilities Tarleton and Ward (2007), in their study into parenting with support, recommend that such services to be provided in a ‘joined-up’ approach. Apart from Tarleton and Ward's study, the literature yielded little, if any, evidence for structures or processes that could facilitate health or maternity care for women with intellectual disabilities. It is generally acknowledged that this is an under-addressed and under-researched field.

There have, however, been a number of generic developments, both nationally and internationally, which may become vehicles for the development of appropriate and positive service responses to women with intellectual disability. The United Nations Convention on the Rights of the Person with Disabilities (United Nations (U.N), 2006), which Ireland has signed up to, affirms that people with disabilities have the right to parenthood, fertility, reproduction, family planning (Article 1) and to 'the same range, quality and standard of free or affordable health care and programmes…in the area of sexual and reproductive health…' (U.N., 2006: Article 25). At the time of writing Ireland has not yet ratified the Convention.

In Ireland, the publication of the Disability Act (Government of Ireland, 2005) provides a statute-based right for people with disabilities to have an independent assessment carried out in relation to their disability-related health needs. The National Standards for Needs Assessment issued by the Health Information and Quality Authority (2007) provide protocols for referral to services such as maternity services within the assessment of needs process.

6.4. Summary

Access to maternity services by women with intellectual disabilities is an under-researched area, and their experiences of pregnancy, childbirth and early motherhood are not well described. The research that exists in this area documents widespread negative attitudes towards the idea of women with intellectual disabilities becoming pregnant and taking on the role of parents. Providing support for women with intellectual disabilities as they experience pregnancy, childbirth and early motherhood is the main suggestion for improvement that arises from the literature. Recent legislation may lead to improved access to maternity services for women with intellectual disabilities in Ireland.

Section Three: Planning for the future

Chapter Seven: Summary and conclusion

7.1. Summary

7.1.1. Overview

Women with disabilities represent a diverse group experiencing a variety of disabling conditions, all of whom require and have a right to individualised care. The National Disability Survey showed about 20,000 women aged 18 - 34 and about 18,500 women aged 35 - 44 had a disability in one or more of the 9 categories used in the survey (National Disability Survey vol. 1 Table 5B). The most frequently cited conditions for women of childbearing age were mental health conditions, pain, mobility, intellectual and learning disability, and difficulties in remembering and concentrating.

Evidence from the literature showed that society has tended to undervalue and discriminate against women with disabilities, and has, particularly in the past, exerted control over their sexual and reproductive lives (Waxman, 1993; Kallianes and Rubenfeld, 1997; Kaplan, 2006). Accessing information with regard to sexuality, and obtaining quality individualised reproductive care is especially difficult for women with disabilities as they are often perceived as asexual and not likely recipients of such care (NWCI, 2006; Piotrowski and Snell, 2007).

Maternity care across the world has become increasingly medicalised, which has led to a diminution of emphasis on the importance of women's experiences during pregnancy and childbirth. Many women, irrespective of their disability status, are unhappy with aspects of their care during pregnancy or birth in Ireland (O'Doherty and Regan, 2006). To have a disability when accessing maternity services, therefore, is to be doubly disadvantaged. The barriers and facilitators experienced by women with a disability when accessing the health and maternity services during pregnancy, childbirth and early motherhood were noted under the 5 headings of: availability, accessibility, accommodation, affordability and acceptability.

7.1.2. Barriers to accessing services for women with disabilities

7.1.2.1. Availability of services for women with disabilities

In general, services were available in most countries for women with physical disabilities or sensory impairments, but whether the care was appropriate and accessible was questionable. There were, however, poor links between maternity and mental health services (Currid, 2004; Commission for Healthcare Audit and Inspection, 2008), and it was difficult to discover if any suitable services were available for women with intellectual disabilities.

7.1.2.2. Accessibility of services for women with disabilities

Accessibility of services, in the main, related to the location and models of care, difficulties in transport and moving around the physical environment. For women with sensory impairment there was an identified need to improve access to buildings and services (Nzegwu, 2004), with emphasis on the difficulties of completing registration forms, locating a seat in the waiting area, and realising when to go into the examination room (Ubido et al, 2002). In some instances physical, architectural and communication barriers were so prominent that the availability of particular services were at a sub-optimal level (Miller and Finnerty, 1996; Fiduccia, 1997; Grabois, 2001; D'Eath et al, 2005). Women with mental health difficulties needed particular encouragement to overcome the possible lack of motivation to attend clinics (Zittel-Palamara et al, 2008) or even, rarely, special assistance if they denied the pregnancy totally (Apfel and Handel, 1993; Nicholson et al, 1998a).

7.1.2.3. Accommodation of women with disabilities

Barriers to accommodation centred mainly on the lack of provision of suitable disability-specific health information for women (Conine et al, 1986; Carty et al, 1993). In particular, women with sensory impairments needed information provided in alternative formats (Jones et al, 2007), and all women required information on the existence of mental difficulties in pregnancy and the postnatal period, and of services available to them (Buultjens and Liamputtong, 2007). There were difficulties with communication, caused by physical mal-positioning of reception desks and staff (McKay-Moffat, 2007), and a lack of appreciation of the needs of women with sensory impairments. Interpersonal skills, aids and services were typically deemed inappropriate by women with disabilities, irrespective of their type of disability. This impacted on the issue of informed consent (McEvoy et al, 1983; Mowbray et al, 1995a; Grabois, 2001), resulted in a deficit of information for expectant and/or new parents and contributed to impaired autonomy, decreased self-confidence, self-esteem and self-worth (Thomas, 1997; Tilley, 1998; Walter et al, 2001; Prilleltensky, 2003).

Maternity care professionals had little knowledge about the effects of physical disabilities on pregnancy (Westbrook and Chinnery, 1995; Smeltzer et al, 2007) and the capability of women with all types of disability to parent. In addition, their lack of knowledge of the effects that mental health difficulties had on pregnancy, childbirth and early motherhood (Wiley et al, 2004) led to poor screening practices and inappropriate care (Robinson, 2007).

7.1.2.4. Affordability of services for women with disabilities

Women with mental health difficulties were identified as having barriers in the area of affordability (Anderson et al, 2006), as many are from low income families and the costs of childcare and transport may also prevent them from accessing health care services.

7.1.2.5. Acceptability of services for women with disabilities

Health professionals' lack of knowledge and negative attitudes led to barriers in acceptability, as women did not feel respected or supported (Steinberg, 2006; Commission for Healthcare Audit and Inspection, 2008) and health professionals failed to recognise and appreciate their needs. Evidence from the literature reveals how healthcare workers primarily viewed all mothers with a disability as being dependent recipients of care and services. Women perceived that their right, ability and capacity to parent were constantly met with scepticism (Harris and Bamford, 2001; Prilleltensky, 2003, 2004) and women reported that they felt continually scrutinised, particularly those with an intellectual disability or enduring mental health difficulties (Prilleltensky, 2003; Grue and Tafjord-Laerum, 2002). Women with mental health difficulties appeared to have the most obstacles to surmount, including overcoming a reluctance to admit to their illness, due to the stigmatisation of mental health disorders, and the fear of being judged a 'bad mother' (Edhborg et al, 2005; Davies and Allen, 2007). The fear of losing custody of their child led, in many instances, to lack of trust in health care providers (Montgomery et al, 2006; Jesse et al, 2008) and the feeling that they were continually having to prove themselves to the authorities. Struggling to be accepted as ordinary and to be considered within the concept of normality, mothers felt vulnerable (Conley-Jung and Olkin, 2001; Llewellyn et al, 2003) and went to great lengths to present themselves as managing the transition to parenthood competently.

Women with intellectual disabilities encountered society's negative attitudes to them becoming pregnant and caring for their children also (Cuskelly and Bride, 2004; Drummond, 2006), with a resulting lack of support networks for them during pregnancy, childbirth and early motherhood (Aunos et al, 2008). Children of mothers with intellectual disabilities or mental health difficulties were often taken into custody, despite a lack of evidence of harm to them. Following such removal, parents were often unrepresented in the court proceedings and formal court interventions were not activated to help parents regain custody (Swain and Cameron, 2003).

7.1.3. Facilitators to improve access to services for women with disabilities

Facilitators to access that were identified for women with all disabilities included improved physical access to all care areas, the provision of sensitive antenatal education classes (Conine et al, 1986; Carty et al, 1993) and education of health professionals to improve their knowledge of, and attitudes towards, women with disability (Baker et al, 1997; Smeltzer, 2007). Specific disability awareness and training for health professionals, particularly in speaking correctly for lip-readers (RCN, 2007), and in the use of basic sign language is recommended in the literature. The use of telephone amplifiers and/or pictorial signage, audible, visual and tactile systems in waiting rooms and information provided in an appropriate language and format were all noted to be useful in improving accessibility to services (Clark, 2002; Nzegwu, 2004). It was also found that the employment of sign language interpreters in appropriate languages is useful for women with sensory loss who are from ethnic minority groups (Pierce, 2003).

For women with mental health difficulties, improved communication between professionals in maternity services and those in mental health care was seen as desirable (Shakespeare et al, 2003), with emphasis on the provision of more counselling services instead of drugs (Edge and Rogers, 2005; Edge, 2006). The key Irish study of the experiences of people with disabilities of the health services, commissioned by the National Disability Authority (D'Eath et al, 2005), reported some positive experiences particularly in relation to care provided by General Practitioners. People with mental health difficulties, however, did not experience the same degree of partnership approaches and inclusive practices

(D'Eath et al, 2005). The introduction of telesupport or web-based support groups (Ugarriza, 2002), the provision of designated perinatal multidisciplinary teams in the community (Oluwatayo and Friedman, 2005), and the introduction of more specialist mother and baby psychiatric units were also promoted (Lewis, 2007).

7.2. Conclusion

The National Disability Authority and National Women's Council of Ireland have previously highlighted the need to improve access to reproductive and sexual health services for women with disabilities in Ireland, as well as the need for disability awareness training among health professionals (NWCI, 2001; NDA, 2007). Evidence from the NDA's second national survey suggests that the public's attitudes towards disability are improving (NDA, 2007). The literature presented here shows that in many countries women with disabilities have reported that services do not adequately meet their needs and emphasises the need to improve the care services for women with disabilities attempting to access health care during pregnancy, childbirth and early motherhood.

The dearth of literature in this review from the Irish perspective highlights the importance of the current study commissioned by the National Disability Authority, of which this review forms the first part. The second part, which leads on from and is complementary to this paper, is a review of Irish and international social policies relating to disability and childbirth (Begley et al, 2009). These 2 documents demonstrate a need for comprehensive policy development and planning in consultation with women with disabilities to provide an improved response to the maternity service needs of this group.

The starting point for any change in service provision has to be with the individuals seeking that service (Kennedy and Murphy-Lawless, 2002), so if access to health services during childbirth, pregnancy and early motherhood is to be improved for women with disabilities, their experiences must be documented. The third section of the NDA-commissioned work, therefore, is a study to explore the strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood (Begley et al, 2010). This study gathered information from women with physical disabilities, visual or hearing impairment, intellectual disabilities or mental health difficulties, throughout the country, with a view to informing the development and improvement of maternity care services for women with disability in Ireland.

Chapter Eight: Key research findings and research gaps identified

8.1. Key research findings

8.1.2. Introductory findings

- Maternity care in western society has become increasingly medicalised, which has led to a diminution of emphasis on the importance of women's experiences during pregnancy and childbirth.

- Sixty-three percent of a sample of 500 mothers from the general population in Ireland was unhappy with aspects of their care during pregnancy or birth.

- In Ireland, approximately 38,000 females between the ages of 18 and 44 years have a disability of some type.

8.1.3. General findings

- Evidence in the literature suggests that society has, in many instances, undervalued women with disabilities and the care of women with all types of disabilities shows a history of discrimination that lasts to the present day.

- It would appear from the literature that society has exerted control over the sexual and reproductive lives of women with disabilities and, particularly in the case of mothers with intellectual or mental health disabilities; there is often a presumption of risk to the child, whether or not there is evidence of such risk.

- Adverse societal attitudes such as these may very well lead to barriers for women with disabilities in accessing suitable services in pregnancy, childbirth or motherhood.

8.1.4. Findings in relation to women with physical disabilities

Barriers for women with physical disabilities were found in relation to:

- accessibility, related to the location and models of care, difficulties in transport, and moving around the physical environment
- accommodation, centred mainly around the lack of provision of suitable health information and less so around difficulties with communication
- acceptability, in terms of lack of knowledge and negative attitudes and behaviours from staff.

Facilitators to access for women with physical disabilities were more difficult to ascertain from the published literature, but some were found in relation to:

- accessibility, relating to improving access to buildings and services, with some emphasis on developing ease of movement around the physical environment
- accommodation, focussing on the provision of sensitive antenatal education classes
- acceptability, noting that considerable work on developing health professionals' knowledge of, and attitudes towards, physical disability is required.

8.1.5. Findings in relation to women with sensory impairments

Barriers for women with sensory impairments were found in relation to:

- accessibility, which focussed mainly on the difficulties of orientation to the health care setting, completing registration forms, locating a seat in the waiting area, and realising when to go into the examination room

- accommodation, which centred mainly around communication and health education, where women with hearing impairment, in particular, were at a great disadvantage
- acceptability, which related to how women with sensory disabilities tend not to feel respected or supported and have reported that some health professionals fail to recognise and appreciate their needs.

Facilitators suggested in the published literature to improve access for women with sensory impairments were slight, but some were found in relation to:

- accessibility, including the use of telephone amplifiers and/or pictorial signage, Braille, audible, visual and tactile systems in waiting rooms and information provided in an appropriate language and format
- accommodation, focussing on the need for extended consultation times and culturally sensitive antenatal education classes
- acceptability, relating to disability awareness and training for health professionals, particularly in speaking correctly for lip-readers, and in the use of basic sign language; education of health professionals should perhaps incorporate education by women with disabilities themselves.

It was also found that the availability of sign language interpreters in the appropriate languages is useful for women with sensory loss who are from ethnic minority groups.

8.1.6. Findings in relation to women with mental health difficulties

Barriers for women with mental health difficulties appeared to be considerably greater, or perhaps were better documented, than for women with other disabilities, and were found in relation to:

- availability of appropriate care, as there are poor links between maternity and mental health services
- accessibility, in relation to women’s mental state, as they may lack motivation to attend clinics or may even, rarely, deny the pregnancy totally

- accommodation, where the women's considerable needs included lack of knowledge of the existence of mental difficulties in pregnancy, and the postnatal period and of the services available to them; lack of knowledge of maternity care professionals about mental health issues; and poor screening practices
- acceptability, centred mainly around a reluctance to disclose their illness, and distress due to society's, and their family's, stigmatisation of mental health problems; fear of being judged 'a bad mother'; losing custody of their child; taking medication that might affect the fetus or baby while breast-feeding, or impair their ability to care for their children; lack of trust in health care providers and the feeling that they are continually having to prove themselves to the authorities
- affordability, as many are from low income families and cannot afford to pay for costs of childcare and transport, which may prevent them from accessing health care services.

Few facilitators to improve access for women with mental health difficulties were mentioned in the literature, but some were found in relation to:

- availability, by providing training and education of health professionals to improve communication between professionals in maternity services and those in mental health care; through introducing telesupport or web-based support groups; by providing designated perinatal multidisciplinary teams in the community, including psychologists and social workers, and specialist mother and baby psychiatric units
- accessibility, in particular encouraging health professionals to develop more trust with their clients
- accommodation, noting the need to provide education for women about mental illness and the services available to them and to provide support groups
- acceptability, where training and education of health professionals and family meetings were suggested as a means to decrease the negative attitudes encountered; through supportive partnerships between women

and health professionals where they would be treated with respect, and their strength acknowledged; relating to the need for continuity of care, help in communicating with their children, and more counselling services instead of drugs (with non-national women preferring counsellors from their own cultural background)

- affordability, regarding the provision of childcare facilities at clinics and practical help with mothering.

8.1.7. Findings in relation to women with intellectual disabilities

Barriers for women with intellectual disabilities were found in the literature in relation to:

- society's negative attitudes to women with intellectual disabilities becoming pregnant, and caring for their children, with a resulting lack of support networks for women with intellectual disability during pregnancy, childbirth and early motherhood;
- conservative and protective perspectives from frontline caring staff and parents regarding the sexuality of women with intellectual disability, which put the women at risk of coercive sterilisation or forced contraception.

Research on facilitators to access to maternity services for women with intellectual disabilities was almost non-existent. The Disability Act (Government of Ireland, 2005) places statute-based obligations on public bodies to provide accessible services and information.

8.2. Key research gaps

It is recommended that all future research in the area of women's health should include women with disabilities, as appropriate. Through this review, research gaps have been identified in the following areas in relation to general maternity and health service care and in relation to women in the 5 categories of disability:

8.2.1. General maternity and health service care

- The attitudes of society in relation to women with disabilities, in particular in relation to their sexual and reproductive lives and the issue of taking custody of their children.

8.2.2. Research on the care of women with any of the disabilities during pregnancy, childbirth and early motherhood

Research gaps have been identified in the areas of:

- locations and models of maternity care for women with any disability
- transport difficulties experienced by these women
- the physical environment in maternity hospitals and its effect on women with any disability
- the provision of health information for these women
- knowledge, attitudes and behaviours of health care staff towards women with any disability.
- the adequacy of consultation times between women with disabilities and health care professionals.

8.2.3. Research on the care of women with specific disabilities during pregnancy, childbirth and early motherhood

In addition, research gaps have been identified in the area of:

- communication needs for women with sensory impairments when accessing the maternity services
- the links between maternity and mental health services
- the motivation of women with mental health difficulties to attend clinics
- women’s knowledge of the existence of mental health difficulties in pregnancy and the postnatal period and of the services available to them
- knowledge of maternity care professionals about mental health issues
- screening practices for mental health difficulties in pregnancy and the postnatal period.

Some of the above research gaps are addressed by parts 2 and 3 of this study commissioned by the NDA to review social policy documents in relation to women with disability and to explore the strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood.

8.2.4. Research on the care of women with intellectual disabilities during pregnancy, childbirth and early motherhood

Due to the lack of comprehensive investigative work concerning maternity care for women with intellectual disabilities, an extensive programme of exploratory research is required to ascertain their views and experiences as they journey through pregnancy, childbirth and early motherhood. This can form the basis of further work targeted at developing specific aspects of care identified as lacking or below quality. The first stage of this exploratory work was addressed as one section of part 3 of this study commissioned by the NDA.

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Appendices

Appendix 1 – Definitions of disability

How the term ‘disability’ is defined and understood can have implications for how people with disabilities are treated and perceived. The authors understand that there is a tendency to view people with disabilities as one homogenous group and are aware that a range of factors such as gender, class, sexuality and age structure the experience of people with disabilities. There are many definitions of ‘disability’ and the issue of a definition has proven to be one of the most contentious issues facing the delegates of the United Nations committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities. In 2006 the following definition was proposed as a ‘working proposal’

‘Disability results from the interaction between persons with impairments, conditions, or illnesses and the environmental and attitudinal barriers they face. Such impairments, conditions, or illnesses may be permanent, temporary, intermittent, or imputed, and those that are physical, sensory, psychosocial, neurological, medical or intellectual.’

The International Classification of Functioning Disability and Health (ICF) provided the following definition of disability:

‘Disability is a decrement in functioning at the body, individual or societal level that arises when an individual with a health condition encounters barriers in the environment’.

Either of the 2 above definitions clearly express the essential structure of the concept of disability as a result of an interaction between features of an individual with a health condition and features of the physical, individual and societal environment. It clearly recognises the 3 dimensions of disability (body, individual and societal levels) to increase inclusiveness and to be applicable to the full range and diversity of disability experience at the same time. It further ensures inclusiveness and the complete coverage of all relevant disability rights issues, by defining disability as to apply to a person with impairment alone, or an activity limitation alone, or a participation restriction alone (WHO, 2001).

The definition used in the Disability Discrimination Act, 1995 (United Kingdom Parliament,1995) is as follows:
‘A physical impairment that has a substantial and long term adverse effect on a person’s ability to carry out normal day to day activities’.

The Disability Act (Government of Ireland, 2005) defines disability as 'a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment (pg.6).'The definition of disability contains the concept 'substantial restriction' and this is seen as a restriction which - (a) is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and (b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability (Government of Ireland, 2005).

Explanations of:

Impairment

The definition covers physical and mental impairments. These include:
- physical impairments affecting the senses, such as sight and hearing
- mental impairments including learning disabilities and mental illness (if it is recognised by a respected body of medical opinion).

Substantial

For an effect to be substantial, it must be more than minor.
The following are examples that are likely to be considered substantial:
- inability to see moving traffic clearly enough to cross a road safely
- inability to turn taps or knobs
- inability to remember and relay a simple message correctly.

Long-term

These are effects that
- have lasted at least 12 months, or
- are likely to last at least 12 months, or
- are likely to last for the rest of the life of the person affected.

Long-term effects include those which are likely to recur. For example, an effect will be considered to be long-term if it is likely both to recur, and to do so at least once beyond the 12-month period following the first occurrence.

Day-to-day activities

Day-to-day activities are normal activities carried out by most people on a regular basis, and must involve one of the following broad categories
- mobility - moving from place to place
- manual dexterity - for example, use of the hands
- physical co-ordination
- continence
- the ability to lift, carry or move ordinary objects
- speech, hearing or eyesight
- memory, or ability to concentrate, learn or understand
- being able to recognise physical danger (DHSSPS, 2005).

Appendix 2 – Major organisations and experts contacted

Contact	**Purpose**
Irish Wheelchair Association	Locate any work previously done in this area
Irish Deaf Society	Locate any work previously done in this area
National Council for the Blind	Locate any work previously done in this area
Women's Studies, TCD	Locate any work previously done in this area
Centre for Deaf Studies, TCD	Locate any work previously done in this area
Disability Services, TCD	Locate any work previously done in this area
School of Law, TCD	Locate any work previously done in this area
Emily Steinberg, U.S.A.	Discuss study previously conducted in this area
Carolyn Frohmader, Australia	Discuss study previously conducted in this area
Margaret Nosek, Australia	Discuss study previously conducted in this area
Deaf hear organisations	Locate any work previously done in this area
Dr. Malachy Feely Nurse Advisor, Department of Health and Children	Locate any work previously done in this area
Ted Tierney, Mental Health Ireland	Locate any work previously done in this area
Grow	Locate any work previously done in this area
Aware	Locate any work previously done in this area
Schizophrenia Ireland	Locate any work previously done in this area
Health Research Board	Locate any work previously done in this area
Dr. McCarthy Consultant Psychiatrist Rotunda Hospital Dublin	Locate any work previously done in this area
Dr. Sheehan Consultant Psychiatrist National Maternity Hospital Dublin	Locate any work previously done in this area
Yulia Kartalova-O'Doherty, Mental Health Research Unit in the Health Research Board	Obtain data from the National Psychological Wellbeing and Distress Survey

Appendix 3 – Tables 2 and 3

Table 2: Studies describing barriers to accessing services among women with physical disabilities

Table 3: Studies describing facilitators to accessing services among women with physical disabilities

Table 2: Studies describing barriers to accessing services among women with physical disabilities

Author(s) & Year	Country	Aim	Methodology	Population Group/ Sample Size	Barriers to accessing services
Anderson & Kitchin (2000)	Northern Ireland	To examine the level of access for women with disabilities to family planning clinics and sexual education and information in Northern Ireland.	Quantitative. Self reported questionnaire	54 family planning clinics in NI. Response rate of 63% (physical and hearing impairment)	People with disabilities encounter challenges with physical access to family planning clinics. Access to information and services offered by family planning clinics were limited. Expectations that people with disabilities are asexual and these persons continue to experience exclusion and denial of access to reproductive services.
Baker et al (1997)	U.S.A.	To explore the reproductive health care experiences of women with physical disabilities and to recommend improvements.	Qualitative descriptive, exploratory. Semi structured interviews.	10 women with a physical disability aged between 18-50yrs.	Concept of asexuality was prominent. Challenges were encountered in relation to physical access to the facilities and inappropriate equipment. Health professionals were insensitive and there was a general lack of awareness and knowledge about the impact disability would have on pregnancy and vice versa.
Blackford et al (2000)	Canada	To explore the prenatal education and maternity care experiences of mothers with a disability.	Qualitative descriptive, exploratory. Semi structured interviews.	8 women with a chronic illness/disability (physical and visual impairment)	Gaps exist in the information received by women during prenatal education sessions. Women received insufficient and inappropriate information in relation to pregnancy and their disability. The needs of this population are overlooked and women's ability to parent is challenged.

Clark (2002)	U.K.	To explore accessibility of health information provided by NHS to people with disabilities.	Quantitative. Review key information booklets and leaflets.	130 people with a physical and sensory disability.	People with disabilities do not receive health information in appropriate formats.
Conine et al (1986)	Canada	To examine the availability of preventative maternal health care and the provision of childbirth education services to women with a physical disability in Vancouver	Quantitative. Self reported survey.	20 agencies in Vancouver that provide childbirth education services for women with a physical disability.	Childbirth education for women with a physical disability is limited; women are usually referred elsewhere. Challenges encountered with physical accessibility. Educators do not consider provision of classes for this population as part of their function. Educators lack knowledge about the impact pregnancy will have on disability. Not willing to embrace concept of normality and mainstreaming of this population.
D'Eath et al (2005)	Ireland	To explore the experiences of people with disabilities in accessing mainstream health services.	Qualitative descriptive, exploratory. Unstructured interviews.	32 participants, 12 women, 15 men with disability, 5 relatives/ advocates. 4 women with disabilities (physical and hearing) with experience of maternity services	People with disabilities experience a multitude of inequalities in accessing and utilising the health services. Services are fragmented and uncoordinated, inequalities not addressed by institutions, principles of equity, fairness and person centeredness are not operationalised, and the person's autonomy is impaired by lack of support mechanisms. Communication, physical and attitudinal challenges were frequently encountered and unaddressed.

Grabois et al (1999)	U.S.A.	To determine if primary care physicians and access to their offices are in compliance with U.S.A. Disabilities Act (1990)	Quantitative Cross sectional survey. Self-reported questionnaire	220 physicians (GPs, internists obstetricians). 62 responded. Response rate = 28%.	18% of physicians could not provide a service to people with disabilities and were non-compliant with disability legislation. Barriers were identified in relation to physical access, inaccessible equipment and inappropriate referral of people. Practices were discriminatory.
Grue & Tafjord-Laerum (2002)	Norway	To explore the mothering experiences of mothers with a physical disability.	Qualitative descriptive, exploratory. Semi structured interviews.	30 women with a physical disability aged between 28-49 years	Becoming a mother afforded women a sense of normality, focus was on mothering not disability. Women had to overcome societal attitudes that perceived them as different to the norm. Perceived as dependent recipients of care rather than autonomous carers. Fear that their children will be taken into custody.
Jackson & Wadley (1999)	U.S.A.	To determine reproductive conditions, potential complications and behaviours in women post spinal cord injury.	Quantitative. Questionnaire.	472 women, one year post spinal cord injury.	Reproductive health concerns of women with spinal cord injury. Sexual experiences and complications associated with the injury are discussed. Challenges in access to reproductive health care were encountered.
Lipson & Rogers (2000)	U.S.A.	To develop a greater understanding of women's experiences of and their satisfaction with the health care services utilised during pregnancy,	Qualitative. Semi structured interviews.	12 women with mobility limited physical disability.	Women's experiences shaped by 3 factors – specific disability, resources, personality and approach to pregnancy. Health professionals had little experience and lacked awareness and knowledge of pregnancy and disability. No referral to allied professionals. Birth experience was medicalised and technology used frequently. Postpartum health professionals were insensitive, communication was

		birth and the postpartum period.			inappropriate and referral mechanisms nonexistent.
McKay-Moffat & Cunningham (2006)	U.K.	To investigate childbirth experiences of women with a physical disability and to examine the experiences of midwives providing care to women with a physical disability during childbirth.	Qualitative descriptive, exploratory. Semi structured interviews.	8 midwives, and 5 mothers with a physical disability.	Five themes emerged from mothers – their quest for normality, the disability taking precedence over pregnancy, midwives' lack of awareness and knowledge about the women's disability, importance of disability awareness and positive attitudes for midwives, the need for effective communication. Three themes emerged from the midwives' perspective – midwives' varied knowledge and experience, positive attitudes and positive communication.
McKeever et al (2003)	Canada	To investigate the mothering experiences of mothers with a physical disability	Qualitative descriptive, exploratory. Unstructured interviews.	11 mothers with a physical disability using wheelchairs and scooters	Mothering experience influenced by ability to access the physical environment and home care services. Assistance was rarely given despite an identified need. Impaired mobility impacts on the mothering role.
Mitton et al (2007)	U.K.	To explore health and life experiences of mothers with rheumatoid arthritis.	Qualitative. Semi structured interviews.	7 women with rheumatoid arthritis aged between 21-41 yrs.	Five themes emerged from women's experiences: inner strength gained from their illness, their illness was an antecedent to depression, women were labelled despite their desire to feel normal, felt like a failure as wife and mother. Women expressed the need for education about their illness and its effect on pregnancy and associated complications.
National Disability Authority (NDA) (2002)	Ireland	To explore the general population's perceptions of disability and	Quantitative. Social survey interviews.	1,000 adults from the general population.	Positive and negative public attitudes in relation to a variety of topics including defining disability, treatment of people, education & employment and difficulties encountered by people with disabilities, who is responsible for

		people with disabilities.			caring for them, the rights of people with disabilities to have relationships and be sexual.
National Disability Authority (NDA) (2007)	Ireland	To explore the general population's perceptions of disability and people with disabilities	Quantitative. Social survey interviews.	1,004 adults from the general population.	Public attitudes were more positive than in the 2002 survey. Attitudes were determined in relation to the same topics as in the 2002 survey (above)
Nosek (1995)	U.S.A.	To examine barriers to reproductive health maintenance among women with physical disabilities.	Qualitative descriptive, exploratory. Unstructured interviews.	31 women with a physical disability.	Physical and attitudinal challenges were encountered by women when accessing reproductive health care. Health professionals were insensitive to women and care was influenced by medical systems. An analytic model towards disability is suggested to influence a person's behaviour and reproductive health.
Nosek (2001)	U.S.A.	To examine the broad range of issues that women with a physical disability encounter in relation to sexual functioning, and sexual and reproductive health care	Triangulation – Qualitative and quantitative. Unstructured interviews and questionnaire.	Qualitative – 31 with a physical disability Quantitative – 1,150 women, of whom 946 completed the questionnaire (504 with and 442 without disability). 45% response rate	Women with disabilities have difficulty establishing relationships, social and environmental factors impact on women's self esteem, abuse was prevalent among women, women had sexual desires but limited opportunity to participate in sexual activity, women with physical disabilities encounter challenges when accessing reproductive health care including difficulty locating a physician to administer care.
Pierce (2003)	Ireland	To investigate how people with multiple	Qualitative interviews.	9 minority ethnic people with	Minority ethnic people are invisible in Irish society. This population encounters difficulties

		identities understand their identities and sense of belonging to different social groups. To examine their experiences of accessing public health services.		disabilities (physical and hearing impairment).	in getting to and obtaining physical access to health care institutions. They encounter negative attitudes, language and communication challenges. Health professionals lack cultural awareness and did not respond to people's health need with any degree of urgency. Care was not culturally sensitive.

Prilleltensky (2003)	U.S.A.	To explore the meaning of motherhood for mothers with a physical disability and to determine their mothering related experiences, issues and priorities.	Qualitative. Interviews and focus groups	35 women with a physical disability.	Women experienced a variety of responses to their pregnancy including opposition and scepticism. Women's needs and level of formal support varied and depended on the disability. Women emphasised the need to retain control over their mothering role and lack of adequately funded resources was identified as a major challenge which impacted on their parenting abilities.
Smeltzer (1994)	U.K.	To identify and explore the specific concerns and issues for women with multiple sclerosis during pregnancy.	Qualitative interviews.	15 women with multiple sclerosis	Women struggled with decision to become pregnant as they did not know the impact pregnancy might have on MS. MS was considered an abnormal state but becoming a mother facilitated a sense of normality and a change in roles and focus, from dependent women with a disability, to independent autonomous mother. Negative reactions to pregnancy from family, friends and close relatives.
Smeltzer et al (2007)	U.S.A.	To explore women's perceptions of barriers to obtaining care, sources of information, ways to improve health care and health information.	Qualitative. Focus groups. Online survey.	61 - 59 women with a physical or sensory impairment. 2 physicians with an interest in women with disabilities.	The 7 themes (below) indicate the challenges experienced by the study population: Communication barriers, lack of knowledge and awareness among healthcare providers, access issues, working the system, systems issues, outreach to healthcare providers, reaching hard to reach women with disabilities.
Thomas & Curtis (1997)	U.K.	To explore the social barriers women with a physical and/or	Qualitative. Semi structured	17 women with a physical disability and/or	Challenges include difficulties gaining physical access and moving around the environment. Women did not receive information about

		sensory impairment encounter when thinking about having a baby, during pregnancy, when they access maternity and related services and become mothers.	interviews.	sensory impairment.	accessible facilities and resources. Deficits in health information were common and any information given was often contradictory. Practice and policies were inflexible and not women centred. Help was often inappropriate and women felt a burden. Fear of losing custody common and women were afraid to ask for help fearing this may be considered as their inability to cope and care for their baby.
Thomas (1997)	U.K.	To explore key dimensions of the reproductive experiences of women with a disability and/or sensory impairment who are or who are thinking about becoming mothers.	Qualitative. Semi structured interviews.	17 women with a physical and/or sensory impairment.	Three themes: The first refers to medical risk discourse which women accepted. Genetic counselling was viewed as the norm and termination of pregnancy either an option or recommendation. Women's self belief that they could fulfil mothering responsibilities was impaired. Second theme: mothering - women feared they were being judged and that they would lose custody. Felt vulnerable and insecure. Third theme: inappropriate help that health professionals offered to the detriment of women's self-esteem and confidence.
Veltman (2001)	Canada	To examine extent, access to and satisfaction with primary health care services for people with physical disabilities living in the Toronto region.	Quantitative. Question-naire.	1026 people with disabilities. 201 completed questionnaires were returned. Response rate = 20%.	Findings indicate that people with a disability have difficulty locating a physician and were refused treatment because of their disability. People experience difficulty in gaining physical access to the built environment and the majority of people felt that the care they received was inappropriate.
Westbrook and	Australia	To compare child-bearing and early	Qualitative. Structured	70 women – 25 women with a	Experienced barriers in prenatal education classes and within the maternity care setting.

Chinnery (1995)		childrearing experiences of mothers with and without physical disabilities. To compare the support received.	interviews.	physical disability and 45 women without.	Major obstacles encountered were negative attitudes. Health professionals described as domineering, displayed bullying behaviours and did not take account of women's special needs. Prenatal classes unhelpful and inappropriate. Staff described as rude, unhelpful, and unsupportive
Women's Health Council (WHC) (2004)	Ireland	To identify issues to be addressed when developing a strategy for the future maternity services in the Eastern Regional Health Authority.	Qualitative. Focus groups	16 service providers and 10 services users – 4 women with a disability (3 deaf and 1 with a physical disability).	Findings framed within principles of the health strategy. Participants identified measures that could be taken to ensure maternity services are equitable, fair, women-centred and accountable. Women expressed the desire to be treated individually; requested reform in information provision, continuity of care and effective communication. Women expect staff to be familiar with their needs and different types of disability.
Zitzelsberger (2005)	Canada	To explore relationships between contemporary Western cultural representations of bodies and experiences of women born with a physical disability.	Qualitative. Unstructured interviews.	14 women with a physical disability.	Women perceived themselves to be both visible and invisible in society. The women's body was viewed as undesirable and deviated from the norm. Women's identities were denied and their experiences and lives were seen as insignificant. Others' views impacted significantly on women's ability to cope and their value was defined by their disability.

Table 3: Studies describing facilitators to accessing services among women with physical disabilities

Author(s) & Year	Country	Aim	Methodology	Population Group/ Sample Size	Facilitators to accessing services
Clark (2002)	U.K.	See Table 5	Quantitative. Review key information booklets and leaflets.	130 people with a physical and sensory disability.	The report proposes a number of recommendations that should be adapted in order that health information is available in appropriate formats; this will facilitate informed consent and decision making.
Grue & Tafjord-Laerum (2002)	Norway	To explore the mothering experiences of mothers with a physical disability.	Qualitative descriptive, exploratory. Semi structured interviews.	30 women with a physical disability aged between 28-49 yrs.	Becoming a mother afforded women a sense of normality, the focus was on mothering rather than on disability. Women discuss the efforts they go to in order to address other's attitudes and to be accepted as mothers
McKay-Moffat & Cunningham (2006)	U.K.	See Table 5	Qualitative descriptive, exploratory. Semi structured interviews.	8 midwives and 5 mothers with a physical disability.	Women brought out important themes from their perspective: Importance of disability awareness and positive attitudes for midwives, the need for effective communication. Three themes emerged from the midwives' perspective – midwives' varied knowledge and experience, positive attitudes and positive communication.
McKeever et al (2003)	Canada	See Table 5	See Table 5	See Table 5	Home modifications helped in the mothering roles.
Nosek (1995)	U.S.A.	See Table 5	Qualitative descriptive, exploratory.	31 women with a physical disability.	An analytic model towards disability is suggested to influence a person's behaviour and reproductive health.

Pendergrass et al (2001)	U.S.A.	To determine if the internet can be used effectively to educate women with disabilities about reproductive health.	Quantitative. Survey.	26 women with mobility impairments from the U.S.A. and Canada.	The internet was an effective medium to increase women's knowledge about reproductive health issues. The internet is a valuable education tool and a health information site specifically for women with disabilities will address the information deficit experienced by this population.
Smeltzer et al (2007)	U.S.A.	See Table 5	Qualitative. Focus groups. Online survey.	See Table 5	The authors suggest that women with disabilities should be recognised as a critical source of education.
Women's Health Council (WHC) (2004)	Ireland	To identify issues to be addressed when developing a strategy for the future maternity services in the Eastern Regional Health Authority.	Qualitative. Focus groups	See Table 5	The provision of professional sign language interpreters for each interaction was recommended and more flexible visiting hours to enhance women's support mechanisms requested. Disability awareness and the provision of additional time are key to the facilitation of a positive interaction between staff and women.

Appendix 4 – Tables 4 and 5

Table 4: Studies describing barriers to accessing services among women with sensory disabilities

Table 5: Studies describing facilitators to accessing services among women with sensory impairments

Table 4: Studies describing barriers to accessing services among women with sensory impairments

Author(s) & Year	Country	Aim	Methodology	Population Group/ Sample Size	Barriers to accessing services
Clark (2002)	U.K.	To explore the accessibility of health information provided by NHS to people with disabilities.	Quantitative. Review key information booklets and leaflets.	130 people with a physical and sensory disability.	People with disabilities do not receive health information in appropriate formats.
Conley-Jung & Olkin (2001)	U.S.A.	To explore the experiences of mothers with a visual impairment during the transition to parenthood.	Qualitative descriptive, exploratory. Structured telephone interviews.	42 visually impaired mothers.	The degree of visual impairment does not impact on, nor is it predictive of mothers' parenting experiences. Mothers experienced a variety of attitudes/reactions pertaining to their parenting ability. Tried to conform to sighted ways of parenting; this was a source of frustration and anxiety.
D'Eath et al (2005)	Ireland	See Table 5	See Table 5	See Table 5	See Table 5.
Harris & Bamford (2001)	U.K.	To examine the provision of services for deaf and hard of hearing people.	Qualitative descriptive, exploratory. 5 focus groups.	15 people – 9 deaf and 6 hard of hearing.	Deaf and hard of hearing people are excluded from society. The organisation and provision of services undermine their parental role. Despite policies with the core principle of social inclusion people are still excluded.
Iezzoni et al (2004)	U.S.A.	To examine the health care perceptions and experiences of people who are	Qualitative. Semi structured interviews.	26 people – 14 deaf and between 23-51 yrs and 12 hard of	Physicians and deaf or hard of hearing individuals have conflicting views about being deaf or hard of hearing. There are different perceptions of facilitating effective communication and many physicians do not

		deaf or hard of hearing and provide suggestions to improve care.		hearing between 30-74 yrs.	communicate effectively with this population. Adverse outcomes may result from ineffective communication. Interacting with office personnel is difficult and communication about physical examinations and procedures inadequate.
Kelsall (1992)	U.K.	To investigate the maternity care provided to one deaf woman	Case study.	One deaf woman.	Communication, informational and attitudinal challenges were encountered by deaf women when accessing reproductive health care.
National Disability Authority (NDA) (2002)	Ireland	See Table 5	See Table 5	See Table 5	See Table 5
National Disability Authority (NDA) (2007)	Ireland	See Table 5	See Table 5	See Table 5	See Table 5
Nzegwu (2004)	U.K.	To identify the experiences of visually impaired people when using the NHS. To identify areas of improvement and to address the needs of blind people.	Quantitative. Telephone survey.	832 blind and partially sighted people – 400 owners of guide dogs and 432 not owners of guide dogs	Findings from the survey indicate that visually impaired people experience numerous challenges when accessing services in the NHS especially GP, outpatient and inpatient services. These challenges include – limited physical access to services, limited provision of information in appropriate format, limited staff awareness, limited assistance offered by staff and little assistance provided to guide dog users.
O'Hearn (2006)	U.S.A.	To investigate the factors that	Quantitative. Questionnaire.	55 women – 23 deaf and	Deaf women are less satisfied than hearing women with the care received during the

		impact on deaf women's satisfaction with pre-natal care and compare care of deaf and hearing women.		32 hearing women.	prenatal period. Hearing women had more prenatal visits, received more information and had better communication experiences with their physician than deaf women. Deaf women's rate of satisfaction was influenced by whether or not women's expectations of provision of sign language interpreters were met.
Pierce (2003)	Ireland	See Table 5	Qualitative. Interviews.	9 minority people with disabilities.	See Table 5
Royal National Institute for the Deaf (RNID) (2004)	U.K.	To determine if anecdotal evidence suggesting widespread insufficient quality treatment for deaf people was true.	Quantitative. Survey.	866 deaf and hard of hearing people.	While attending their GP or hospital, deaf or hard of hearing people experience difficulty with communication; some people avoid attending G.P. because of this. Making appointments was difficult, so some were missed, and one third was unclear about instruction regarding medication use.
Smeltzer et al (2007)	U.S.A.	To explore women's perceptions of health care issues - including barriers to care and sources of information	Qualitative. Focus groups. Online survey.	61 - 59 women with a physical or sensory impairment. 2 physicians with an interest in the health care of women with disabilities.	The 7 themes (below) indicate the challenges experienced by the study population: Communication barriers, lack of knowledge and awareness among healthcare providers, access issues, working the system, systems issues, outreach to healthcare providers, reaching hard to reach women with disabilities.

Steinberg (2006)	Ireland	To examine the experiences of deaf Irish mothers as they negotiated access to maternity care services over a 15 year period.	Qualitative. Interviews.	11 deaf women.	Communication and attitudinal barriers were the major challenges experienced by deaf women. Access to information was impaired at both a personal and institutional level. Mothers adapted various methods of communication but health professionals relied on pen and paper and provision of sign language interpreters was limited. Deafness was women's defining characteristic. Health professional's lack of deaf awareness compounded the challenges.
Thomas & Curtis (1997)	U.K.	See Table 5	See Table 5	See Table 5	See Table 5
Thomas (1997)	U.K.	See Table 5	See Table 5	See Table 5	See Table 5
Ubido et al (2005)	U.K.	To examine deaf women's access to health care services in Cheshire U.K.	Quantitative and qualitative. Group discussions and questionnaires.	259 deaf women. 27 participated in qualitative strand. 138 out of 232 were completed and returned.	Deaf women encountered inequalities when accessing health care. Communication was the main problem. Health professionals lacked deaf awareness. Appointments and waiting rooms posed great difficulty; women often missed appointments because they were not aware it was their turn. Stigma existed; they were considered cognitively impaired. Terminology was inappropriate. Women felt embarrassed and frustrated
Women's Health Council (WHC) (2004)	Ireland	See Table 5	See Table 5	See Table 5	See Table 5

Table 5: Studies describing facilitators to accessing services among women with sensory impairments

Author(s) & Year	Country	Aim	Methodology	Population Group/ Sample Size	Facilitators to accessing services
Clark (2002)	U.K.	See Table 7	Quantitative. Review information booklets and leaflets.	130 people with a physical and sensory disability.	The report proposes recommendations that should be adapted to provide health information in appropriate formats to facilitate informed consent and decision making.
Grabois et al (1999)	U.S.A.	See Table 5	See Table 5	See Table 5	The majority of physicians did use auxiliary aids e.g. printed material.
Jones et al (2007)	U.S.A.	To test the effectiveness of the Deaf Heart Health Intervention (DHHI)	Quantitative – quasi experimental pre-post test study over 8 weeks.	84 deaf adults in Phoenix and Arizona.	Developing interventions specifically for deaf adults would facilitate an increase in self-confidence for adopting positive health behaviours.
Kelsall (1992)	U.K.	See Table 7	See Table 7	See Table 7	Measures to overcome communication, informational and attitudinal challenges were identified.
O'Hearn (2006)	U.S.A.	See Table 7	See Table 7	See Table 7	Deaf women's rate of satisfaction was influenced by whether or not women's expectations in the provision of sign language interpreters were met.
Smeltzer et al (2007)	U.S.A.	See Table 7	See Table 7	See Table 7	The authors suggest that women with disabilities should be recognised as a critical source of education.
Women's Health Council (2004)	Ireland	See Table 5	See Table 5	See Table 5	See Table 5

Appendix 5 – Tables 6 and 7

Table 6: Studies describing barriers to accessing services among women with mental health difficulties

Table 7: Studies describing facilitators to accessing services among women with mental health difficulties

Table 6: Studies describing barriers to accessing services among women with mental health difficulties

Author(s) & Year	Country	Aim	Methodology	Population Group/Sample Size	Barriers to accessing services
Jesse et al (2008)	U.S.A.	Explore perceived barriers to seeking help for depression	Focus group interviews	21 pregnant African American and Caucasian low income prenatal women	Lack of trust Stigma and fear of being judged Dissatisfaction with health care system Not wanting help
Zittel-Palamara et al (2008)	U.S.A.	Explore women's desire for postpartum depression (PPD) care	Questionnaire	45 women with PPD recruited through newspaper adverts and referrals from local obstetricians and psychiatrists	Not being sure who to speak to Unable to locate services Symptoms of depression impacting negatively on motivation and ability to take action
Lau and Wong (2008)	Hong Kong	To explore how the Chinese value of 'concern for face' is related to postnatal depression and willingness to seek help	Questionnaires EPDS and Protective and Acquisitive Face Orientation scale (PAFO)	1200 women who had given birth 2-5 days previously completed the questionnaires	Women with depressive symptoms were less likely to seek help than women who were not depressed. Women with high concern for protecting face were 1.36 time less likely to seek help during early postnatal period. Women preferred to seek help from informal sources as opposed to professionals
Teng et al (2007)	Canada	To identify health care workers' perceptions of barriers to care that recent immigrant	Semi-structured interviews	16 professionals (social worker, nurses, family doctor psychologists, psychiatrist) who had an average of 15 years providing	Lack of fluency in English, lack of transportation. Finding and affording a babysitter. Lack of knowledge and understanding of PPD. Cultural barriers, lack of cultural recognition of postnatal depression as a 'medical' problem. Stigma of mental illness and fear of being labelled

		women with postpartum depression may encounter		care to new mothers, with problems including PPD	Fear of shaming the family and desire to maintain family harmony. Lack of spousal support and validation of need to seek help
Alakus et al (2007)	Australia	Explore clinicians' and service users' view on current services and gaps in services provided to parents with mental health difficulties who have children under 5 years	Focused group workshops	34 clinicians recruited from mental health services. Number of service users not identified	Lack of interagency collaboration and communication between services, lack of accessible support groups for parents with young children. Health care professionals not aware of services available and unable to provide this information to service users Lack of knowledge about infant mental health issues among professionals working in adult mental health service. Lack of awareness among maternal and child health that a woman may have a mental health difficulty. Fear of loss of custody
Buultjens and Liamputtong (2007)	Australia	To explore women's experience of postpartum depression (PPD)	Interviews	10 women admitted to a mother and baby unit	Women perceived that the support offered was more focused on the baby rather than mother's needs Shame was a barrier for some women accessing care. Women did not receive education about PPD and were not aware of services available or that mother and baby units existed.
Montgomery et al (2006)	Canada	Describe mothers with serious mental illness experience of mothering	Interviews	20 mothers recruited through a mental health service	Women used strategies to hide their illness, to protect children from discrimination. Women prioritised children's needs over their own. Medication only 'masked' symptoms. Feared hospitalisation as increased risk of custody loss. Health care professionals perceived as having limited understanding of their distress and provided little focused assistance around

					parenting
Anderson et al (2006)	U.S.A.	Explore reason low income mothers with mental health difficulties do not access mental health services	Ethnographic interviews	127 mothers with mental health difficulties who sought treatment for their children at community mental health services.	Prioritising children's needs over own. Fear of custody loss. No health insurance. Lack of transportation and affordable childcare. Perception that health professionals did not understand their life circumstances and problems
Edge (2006) Edge and Rogers (2005)	U.K.	Explore women's experiences and meanings of perinatal depression	In-depth individual interviews	12 Black Caribbean women experiencing postpartum depression (PPD) with babies between 6-12 months, recruited from community health centres and a teaching hospital	Rejecting the label of depression as it is associated with perceived less competence and personal weakness. Fear of discriminatory and coercive treatments. Fear of being only offered anti-depressant drugs resulting in addiction and serious mental illness. Fear of children being taken into care. Cultural imperatives to deny psychological distress not discuss problems outside the home. Unavailability of counsellors from own cultural background. Health care professional attitudes/failure to diagnose. Long waiting lists.
Davies and Allen (2005)	U.K.	Explore women's experiences and interactions with health care professionals	Semi structured interviews	11 mothers with a range of mental health difficulties recruited though community mental health team	Women feel under 'surveillance' from professionals. Women engage in 'impression management' strategies in clinical encounters for fear of judgments being made about their mothering capability. Health care professionals discount women's expertise as mothers

Edhborg et al (2005)	Sweden	To explore and describe Swedish women with depressive symptoms' experience in the first 4 months	Interviews	22 women with PPD recruited through large maternity unit. Babies were aged between 65 and 125 days	Living up to the image of good mother. Shame and guilt at not being happy.
Edwards and Timmons (2005)	U.K.	To consider if women with postnatal illness experience stigma	Semi structured interviews	Six women admitted to a mother and baby unit with post natal illness	The stigma of mental illness results in women not wanting to disclose distress. Fear of loss of custody. Five women had a delay in receiving appropriate help as health care professionals (midwives, GP, health visitor) were slow in recognising the women's distress, discounting it as a 'normal' part of post birth experience. Diagnosis was a relief; however, women were concerned about stigma from organisations if they had to disclose illness in the future, such as emigration, life assurance.
Ugarriza (2004)	U.S.A.	To explore the feasibility of using group therapy for women with PPD and barriers to attending therapy session	Pre and post test using Becks Depression Inventory 11. Ongoing notes	34 women with postpartum depression were asked to participate. 8 women (Hispanic-American and Anglo-American) agreed. Only 6 attended	No woman completed all 10 sessions. Sense of shame and failure at having PPD. Feelings of embarrassment and failure as a woman and mother. Difficulty in adjusting home and family schedule to fit in therapy sessions. Family events clashing with therapy times. Mothers reluctant to attend therapy without child, so if child was ill the mothers stayed at home.

Heneghan et al (2004)	U.S.A.	To explore mothers' beliefs about discussing parenting stress and depression symptoms with their child's paediatrician	Seven focus group interviews	44 women, with a mean age of 27 years, from a variety of socio-economic groups, recruited from 5 community paediatric practices and 1 hospital practice	Mothers in all socioeconomic groups expressed fear of judgment as a 'bad mother' and were fearful of a referral to a child protection agency if they requested help. Mothers in low socioeconomic groups particularly fearful of social work intervention.
Diaz-Caneja and Johnson (2004)	U.K.	Explore the experience of mothers with 'severe mental illness'	Semi-structured interviews	20 mothers with a medical diagnosis of schizophrenia, bipolar disorder and severe depression recruited from community mental health teams Children < 16 years	Children central to women's recovery Medication and symptoms of illness impair ability to mother. Concern over genetic inheritance. Stigma of illness prevented them accessing service and being open. Professional assumptions of 'poor mother' acts as a barrier to being open. Fear of loss of custody. Services withdrawn as soon as crisis is over
Hollingsworth (2004)	U.S.A.	To test hypothesis that individual environmental factors combine with mental illness to predict a history of child custody loss	Quantitative measures of demographic environmental and support variables, and interviews	322 women with severe mental illness, involved in quantitative phase, and 82 in interviews.	Women with persistent mental illness, indicated by hospitalisation, unmarried, household income at or below poverty line, large number of children, lacking parental knowledge, and few social supports are at increased risk of child custody loss. Interview data suggested that substance abuse history and 'troublesome' neighbourhood conditions were present.

Shakespeare et al (2003)	U.K.	To explore acceptability to women of P/N screening by health visitors	Interviews	39 postnatal women attending a GP clinics	21 found screening unacceptable and intrusive. Fear of stigmatising label and custody loss results in women giving false information on screening.
Dipple et al 2002	U.K.	To explore mothers with serious mental illness's experience of mothering	Case note analysis and interviews	58 mothers who were admitted to a long-stay ward in 2 mental hospitals	68% had lost custody of a child, and had little or no contact with them. In 11 cases separation occurred at birth. 57% said separation was against their wishes. 50% of the separations occurred during the mother's fist episode of illness. Women still experienced unresolved grief.
Ugarriza (2002)	U.S.A.	To explore women's experiences and constructions of postpartum depression	Telephone and face to face interviews	30 women with babies 1-12 months old, who self identified as experiencing PPD.	Feelings of shame at not being a 'good mother'. Feelings of guilt at wanting to harm the baby. Lack of knowledge about postpartum depression. Attending support groups too difficult because of logistics of fitting in with an already busy day
Mowbray et al (2001, 2000)	U.S.A.	To explore the life situation of mothers with severe mental illness	Structured interview	379 women carrying out parenting responsibility, with severe mental illness, and recruited from public mental health service in an urban area	63% were mothers before the onset of mental illness. Motherhood was described as a positive experience with positive outcomes such as giving up drugs and ending bad relationships. Women experienced many stresses in life, such as child behaviour problems, financial concerns and parenting alone. Mental health professionals inattentive to parental issues and not supportive. Women expressed need for parental skills training and support.

Chernomas et al (2000)	Canada	Explore women with schizophrenia's perceptions of their illness and needs	Five focus group interviews	28 women who self identified as having schizophrenia, living in community, recruited through health professionals. 15 were mothers	Pregnancies were largely unplanned. 7 women had lost custody of a child. Stigma a barrier to disclosure. Women not informed about family planning, pregnancy or parenting. Concern with taking medication during pregnancy; received conflicting advice from professionals. Side effects of medication impact on ability to parent.
Joseph et al (1999)	U.S.A.	Explore the needs of mothers with serious mental illness	Questionnaires	52 women hospitalised in a state mental hospital with severe mental illness	61.5% had at least one child, 21% had full custody. 12% were the primary carer. Approx 50% described themselves as needing help in dealing with sadness around loss of custody, and help in getting children returned.
Nicholson et al (1998 a) Nicholson et al (1998 b)	U.S.A.	Explore the parenting experience of women with mental illness and case managers views on the problems women face	Focused group interviews	42 mothers who were currently receiving case management were recruited from community services and 55 case managers	Women with mental illness are stigmatised as poor mothers, even before they become pregnant. Mothers' greatest fear was loss of custody or contact with their children. Fear heightened if needed hospitalisation. Constant pressure to prove themselves competent mothers. Mother's mental illness blamed for any problems the child may have. Mothers evaluate themselves against unrealistic standards. Mothers place priority on child's needs and neglect own health. Family members reinforce sick role and do not consult mothers about children's needs.

Table 7: Studies describing facilitators to accessing services among women with mental health difficulties

Author(s) & Year	Country	Aim	Methodology	Population Group/Sample Size	Facilitators to accessing services
Jesse et al (2008)	U.S.A.	See Table 9	See Table 9	See Table 9	Trust. Health care professionals' voluntary offer of support and help
Buultjens & Liamputtong (2007)	Australia	See Table 9	See Table 9	See Table 9	Provide education to women about postnatal illness and service available
Edge (2006) Edge and Rogers (2005)	U.K.	See Table 9	See Table 9	See Table 9	Counselling services more acceptable than drugs. Having access to counsellors from own cultural background
Edwards and Timmons (2005)	U.K.	See Table 9	See Table 9	See Table 9	Meeting other women with similar experience positive
Ugarriza (2004)	U.S.A.	See Table 9	See Table 9	See Table 9	Presence of childcare facilities
Heneghan et al (2004)	U.S.A.	See Table 9	See Table 9	See Table 9	Many barriers to trust were alleviated if mothers had a continued relationship with the paediatrician. Hence, mothers expressed a desire for continuity of care
Diaz-Caneja and Johnson (2004)	U.K.	See Table 9	See Table 9	See Table 9	Group for mothers Family meetings Practical help with mothering Activities for children
Shakespeare et al (2003)	U.K.	See Table 9	See Table 9	See Table 9	Training and education of health professionals
Ugarriza (2002)	U.S.A.	See Table 9	See Table 9	See Table 9	Telesupport or web-based support groups

Appendix 6 – Tables 8 and 9

Table 8: Studies describing barriers to accessing services among women with intellectual disabilities

Table 9: Studies describing facilitators to accessing services among women with intellectual disabilities

Table 8: Studies describing barriers to accessing services among women with intellectual disabilities (ID)

Author(s) & Year	Country	Aim	Methodology	Population Group/Sample Size	Barriers to accessing services
Ager and Littler (1998)	U.K.	To increase awareness of sexual health needs of persons with ID.	Not research article.	Not research article.	Lack of integration between services.
Barr et al (1999)	Northern Ireland	To highlight the need to attend to the health of people with ID.	Retrospective review of health screening.	373 persons with intellectual disabilities.	Lack of integration between services. Lack of awareness of the health needs of persons with intellectual disabilities.
Biswas et al (2005)	U.K.	To explore the uptake of breast and cervical screening by women with ID.	Audit of screening.	48 women with intellectual disabilities.	Difficulty in obtaining compliance and cooperation from women with intellectual disabilities.
Booth and Booth (1993, 1994, 1995)	U.K.	To review the research literature in order to draw out lessons for practice.	Literature review.	Literature review.	Presumptions about parental abilities. Public prejudice and attitudes effectively exclude persons with ID from using services, including maternity services. Social and economic disadvantages have negative effects on ability of people with ID to achieve parental success.
Booth and Booth (2002)	U.K.	To examine the role of men in the lives of mothers who have intellectual disabilities.	Secondary analysis of 3 qualitative studies.	Narrative study – 33 parents, at least 1 with ID (probably mild, but not stated) and 30 adult children with a parent(s) who had ID	The removal of children from parents with intellectual disabilities is associated with intense hardship and grief.

Broughton and Thomson (2000)	U.K.	To explore women with ID's perspectives on the cervical smear test.	Qualitative interviews.	52 women with intellectual disabilities and 34 carers.	Lack of knowledge and information on the part of the women and service providers.
Cuskelly and Bride (2004)	Australia	To examine attitudes about sexual expression of persons with ID	Quantitative study using attitudinal scale.	43 parents of an adult with ID; 62 support staff; 63 community individuals.	Conservative and negative attitudes to sexuality and parenthood.
Ditchfield and Burns (2004)	U.K.	To explore women's experience in respect of their menstrual health.	Qualitative research.	11 women with intellectual disabilities.	Uncertainty and confusion with the menstrual cycle. Negative attitudes to menstruation and, through this, to sexuality.
Drummond (2006)	Ireland	To explore caregivers' and parents' views on sexuality.	Quantitative descriptive.	45 primary carers.	Relationship between attitudes to sexuality of people with intellectual disabilities is influenced by age and religious practice.
Government of Ireland (1993)	Ireland	N/A	Legal statute.	Not research article.	Defines sexual intercourse/or attempted sexual intercourse with a person who is 'mentally impaired' to be a criminal offence.
IASSID SIRG (2008)	International	To set out a position on parenting by persons with intellectual disabilities.	Position paper	Not research article.	Sets out the position of the International Association for the Scientific Study of Intellectual Disabilities on parents and parenting by persons with intellectual disabilities.

Keltner et al (1999)	U.S.A.	To describe and quantify the risk for developmental delay among children born to mothers with intellectual disabilities.	Quantitative research study.	50 mothers with intellectual disabilities and 50 mothers without intellectual disabilities from low income families.	Children born to women with intellectual disabilities are more likely to experience developmental delay, due not to poverty but to inadequate parenting support.
Kohen (2004)	U.K.	To explore mental health needs of women with ID.	Not research article.	Not research article.	Limited access to health care. Services must be able to respond to the needs of women with intellectual disabilities.
Kroese et al (2002)	U.K.	To examine the social support networks of mothers with intellectual disabilities.	Mixed methods.	15 mothers with intellectual disabilities.	Lower numbers of valuable social contacts are associated with reduced self-esteem and greater stress amongst these women.
Lehmann (2005)	Northern Ireland	To examine views that prevent positive sexual health in women with disabilities.	Not research article.	Not research article	Infantilisation of women with intellectual disabilities. Criminalisation of sexual activity on the basis of mental incapacity.
Llewellyn and McConnell (2002)	Australia	To explore the views of mothers with ID regarding support received.	Qualitative interviews.	70 mothers with intellectual disabilities and pre-school children.	Mothers with intellectual disabilities often live outside familial support networks. This is associated with greater stress and poorer health than in the mainstream population.

McConnell and Llewellyn (2000)	U.S.A.	To describe the experiences of parents with intellectual disabilities in court proceedings.	Discursive examination of court proceedings.	Not a research study.	Parents with intellectual disabilities who are already experiencing stress often experience discrimination in statutory child protection proceedings.
McConnell et al (2003)	Australia	To examine the variation in outcomes among children of people with ID.	Randomised controlled trial.	45 parents with intellectual disabilities.	There is little understanding of how women with ID care for themselves during pregnancy. No understanding of the requirements of these women during the antenatal and perinatal stages.
McConnell et al (2008)	Australia	To explore the prevalence of poor pregnancy and birth outcome in women with ID.	Cohort study employing antenatal clinic records.	57 women with intellectual disability and/or self-reported learning difficulties.	There are higher odds of negative birth outcomes for women with intellectual disabilities – pre-eclampsia, low birthweight and admission of baby to the neonatal intensive care unit.
National Disability Authority (NDA) (2007)	Ireland	See Table 5.	See Table 5	See Table 5	Negative attitudes and reactions to disabled women’s sexuality and reproductive health.
Perkins et al (2002)	U.S.A.	To examine mother–child relationships and self-esteem of children of mothers with ID	Quantitative study.	36 children of mothers with intellectual disabilities.	Societal and research foci tend to be on the welfare of children and not on that of mothers.

Rodgers and Lipscombe (2005), Rodgers et al (2006)	U.K.	To explore women's experiences of menstruation and its management	Cross-sectional postal questionnaire survey.	454 questionnaires from women with intellectual disabilities aged between 14 and 55.	Menstruation is problematic for women with intellectual disabilities. Much support is given by carers but more formal education and support is needed.
Sheerin (1998b)	Ireland	To review the literature on parenting by women with ID	Literature review.	Literature review.	The lack of planning for prospective mothers with intellectual disabilities.
Simpson et al (2006)	Northern Ireland.	To examine the feelings, attitudes and experiences of people with ID regarding sex and sexuality	Mixed methods.	>500 people including persons with intellectual disabilities, family carers, frontline staff and professionals.	People with intellectual disabilities often are considered unable to make decisions about their sexuality and reproductive health. Such decisions are frequently made by family carers irrespective of the wishes of the persons with intellectual disability.
Stehlik (2001)	Australia	To examine the reality of institutional violence towards women with disabilities.	Historical research		The effect of eugenics and institutionalisation on women, focusing specifically on motherhood.

Table 9: Studies describing facilitators to accessing services among women with intellectual disabilities

Author(s) & Year	Country	Aim	Methodology	Population Group/Sample Size	Facilitators to accessing services
Broughton & Thomson (2000)	U.K.	See Table 11	See Table 11	See Table 11	Prolonged preparation; improved communication; the giving of information; support for the carers.
Budd & Greenspan (1985)	U.S.A.	The effectiveness of training parents with ID	Quantitative survey.	20 professionals involved in parent-training.	Early intervention in childcare is associated with improved parental outcomes.
Government of Ireland (2005)	Ireland	Legal statute.	Not a research study.	Not a research study.	Sets out the right of persons with disabilities to having an independent assessment of their needs carried out.
Mayes et al (2008)	Australia	To describe the experience of becoming a mother for women with intellectual disabilities.	Phenomenology	17 expectant mothers with intellectual disabilities.	Expectant mothers with intellectual disabilities seek out support from key individuals and develop their own networks.
McConnell et al (2008)	Australia	See Table 11	See Table 11	See Table 11	The use of extended consultation times, communication aids and audio-taping of consultations may improve A/N care.
Simpson et al (2006)	Northern Ireland.	See Table 11	See Table 11	See Table 11	People with ID can make decisions about sexuality and reproductive health if proper education is given to them and their carers.
Tarleton and Ward (2007)	U.K.	To identify supportive structures for parents with ID	Cohort study	30 parents with intellectual disabilities.	Access to supports that are provided in an integrated manner leads to improved parenting outcomes.

Tymchuk (1985), Tymchuk et al (1988)	U.S.A.	To examine ability of mothers with ID to learn effective decision making	Interventional experimental research.	9 mothers with mild levels of intellectual disability	Mothers with mild levels of intellectual disability can learn the main components of decision making.
United Nations (2006)	Geneva	Convention on rights of persons with disabilities.	Not a research study.	Not a research study.	Women with disabilities have a right to equality in terms of 'human rights and fundamental freedoms', and the right to individually-focused health services.