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## **Women with Disabilities: Policies Governing Procedure and Practice in Service Provision in Ireland During Pregnancy, Childbirth and Early Motherhood**

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## Table of Contents

<b>Table of Contents</b> .....	<b>i</b>
<b>Acknowledgements</b> .....	<b>vi</b>
<b>Executive Summary</b> .....	<b>1</b>
1. Introduction .....	1
2. Purpose of review .....	1
3. Outline of review .....	1
4. Key research findings.....	2
4.1. Findings in relation to disability legislation.....	3
4.2. Findings in relation to Irish developments in the care of women with disabilities during pregnancy, childbirth and early motherhood .....	3
4.3. Findings in relation to international policies relating to the care of women with disabilities during pregnancy, childbirth and early motherhood.....	4
5. Conclusion .....	5
6. Recommendations .....	6
1. For the Department of Health and Children.....	6
2. For the Health Service Executive .....	6
3. For professional bodies .....	7
4. For maternity hospitals/units.....	7
5. For clinicians .....	8
<b>Chapter One: Introduction and methodology of review</b> .....	<b>9</b>
1.1. Introduction .....	9
1.2. Purpose of review .....	9
1.3. Definition of “policy” .....	10
1.4. Methodology .....	10
1.5. Number of policies selected .....	12
1.6. Format of the review .....	12
<b>Chapter Two – Background and context of Irish disability policy</b> .....	<b>13</b>
2.1. Introduction .....	13
2.2. Global disability policy: United Nations Standard Rules.....	13
2.3. Global disability policy: United Nations Convention on the Rights of Persons with Disabilities .....	14
2.3.1. The development of the Convention.....	14
2.3.2. Accessibility of services to people with disabilities .....	14
2.3.3. Rights of people with disabilities to health services .....	15
2.3.4. Implementation of the Convention.....	15
2.4. Global policy on disability/equality for women.....	16
2.4.1. United Nations Convention on the Elimination of All Forms of Discrimination Against Women.....	16
2.4.2 United Nations International Conference on Population and Development, Cairo 1994.....	17
2.4.3. United Nations Fourth World Conference on Women, Beijing 1995 .....	17
2.5. Disability policy in Europe .....	19
2.5.1. General disability policy .....	19
2.5.2. National perinatal/maternity mental health policies.....	20
2.6. Health reform in Ireland.....	22



5.1. Introduction .....	59
5.2. Aim of survey .....	59
5.3. Development of the survey instrument.....	59
5.3.1. Initial design .....	59
5.3.2. Testing of questionnaire .....	60
5.4. Accessing the population .....	60
5.5. Data collection .....	60
5.6. Results .....	61
5.6.1. Existence of policies relating to the provision of services for women with disabilities.....	61
5.6.2. Existence of written guidelines for staff assisting women with disabilities.....	62
5.6.3. Assessment of needs of women with disabilities .....	63
5.6.4. Accessibility of services.....	63
5.6.5. Issues regarding care of women with a physical disability.....	64
5.6.6. Issues regarding care of women with a sensory disability .....	65
5.6.7. Issues regarding care of women with mental health difficulties .....	66
5.6.8. Issues regarding care of women with intellectual disabilities .....	67
5.6.9. Disability awareness and training .....	67
5.6.10. Liaison with community services .....	68
5.6.11. Antenatal education.....	68
5.6.12. Feedback on care.....	69
5.6.13. Barriers preventing units from improving services for women with a disability.....	69
5.6.14. Supports needed to improve services for women with a disability.....	70
5.6.15. Additional comments .....	71
5.7. Conclusion .....	71
5.8. Recommendations .....	72
<b>Chapter Six: A comparison of Irish disability policy with international standards</b> .....	<b>73</b>
6.1. Introduction .....	73
6.2. United Kingdom (UK) .....	73
6.2.1. Introduction.....	73
6.2.2. Legislation relating to people with disabilities .....	74
6.2.3. Policies relating to women with physical and sensory disabilities.....	75
6.2.4. Policies relating to women with mental health difficulties .....	78
6.2.5. Policies relating to women with intellectual disabilities .....	82
6.2.6. Recent National Health Service reform .....	83
6.3. The Netherlands .....	85
6.3.1. Introduction.....	85
6.3.2. Legislation relating to people with disabilities .....	85
6.3.3. Policies relating to people with disabilities.....	86
6.4. Sweden.....	86
6.4.1. Introduction.....	86
6.4.2. Legislation relating to people with disabilities .....	87
6.4.3. Policies relating to women with physical and sensory disabilities.....	87
6.5. Norway.....	88
6.5.1. Introduction.....	88
6.5.2. Legislation relating to people with disabilities .....	88
6.5.3. Policies relating to women with physical and sensory disabilities.....	89
6.5.4. Policies relating to women with mental health difficulties .....	90

6.5.5. Policies relating to women with intellectual disabilities .....	90
6.6. Denmark .....	91
6.6.1. Introduction.....	91
6.6.2. Legislation relating to people with disabilities .....	92
6.6.3. Policies relating to women with physical and sensory disabilities.....	93
6.6.4. Policies relating to women with mental health difficulties .....	93
6.7. New Zealand.....	93
6.7.1. Introduction.....	93
6.7.2. Legislation relating to people with disabilities .....	93
6.7.3. Policies relating to women with physical and sensory disabilities.....	94
6.7.4. Policies relating to women with mental health difficulties .....	96
6.7.5. Policies relating to women with intellectual disabilities .....	97
6.8. Australia .....	99
6.8.1. Introduction.....	99
6.8.2. Legislation relating to people with disabilities .....	99
6.8.3. Policies relating to women with physical and sensory disabilities.....	100
6.8.4. Policies relating to women with mental health difficulties .....	103
6.8.5. Policies relating to women with intellectual disabilities .....	103
6.8.6. Recent national reforms and future developments .....	104
6.9. Canada .....	105
6.9.1. Introduction.....	105
6.9.2. Legislation relating to people with disabilities .....	105
6.9.3. Policies relating to women with all disabilities .....	106
6.9.4. Policies relating to women with mental health difficulties .....	108
6.9.5. Policies relating to women with intellectual disabilities .....	110
6.9.6. Recent State reforms.....	110
6.10. United States of America (USA).....	111
6.10.1. Introduction.....	111
6.10.2. Legislation relating to people with disabilities .....	111
6.10.3. Policies relating to women with physical and sensory disabilities.....	112
6.10.4. Policies relating to women with mental health difficulties .....	113
6.10.5. Policies relating to women with intellectual disabilities .....	114
6.11. Summary.....	115
6.11.1. Introduction.....	115
6.11.2. Disability strategies.....	115
6.11.3. Guidelines from professional bodies.....	116
6.11.4. Guideline and policy documents.....	117
6.11.5. Conclusion.....	119
<b>Chapter Seven: Summary, conclusion and recommendations .....</b>	<b>121</b>
7.1. Summary overview.....	121
7.1.1. Disability legislation .....	121
7.1.2. International calls to improve the care for people with disabilities .....	121
7.1.3. Developments in Ireland to improve the care of people with disabilities .....	122
7.1.4. A comparison of Irish and international policies relating to the care of women with disabilities during pregnancy, childbirth and early motherhood ...	123
7.1.5. Discussion .....	124
7.1.6. Conclusion.....	126
7.2. Main policy deficiencies .....	127
7.2.1. At national level .....	127
7.2.2. At Health Service Executive level .....	127

7.2.3. At professional body level.....	127
7.2.4. At individual maternity hospital/unit level .....	128
7.3. Recommendations .....	128
7.3.1. For the Department of Health and Children.....	128
7.3.2. For the Health Service Executive .....	128
7.3.3. For professional bodies .....	129
7.3.4. For maternity hospitals/units.....	129
7.3.5. For clinicians .....	130
<b>References</b> .....	<b>132</b>
<b>Appendices</b> .....	<b>153</b>
<b>Appendix 1. Relevant departments and organisations contacted when sourcing policies.....</b>	<b>153</b>
<b>Appendix 2. The modified Walt and Gilson policy analysis model (1994)...</b>	<b>158</b>
<b>Appendix 3. The survey questionnaire .....</b>	<b>159</b>
<b>Appendix 4. List of 19 publicly-funded maternity units in Republic of Ireland .....</b>	<b>160</b>
<b>Appendix 5. Survey response of the 19 publicly-funded maternity units....</b>	<b>161</b>
<b>Appendix 6. Example of guidelines for women with disabilities .....</b>	<b>166</b>
<b>Appendix 7. Table of policies/legislation/position paper/reviews .....</b>	<b>171</b>

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## 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 comprehensive information on social policies, relating to disability and childbirth, both in Ireland and internationally. The review is one of 3 documents meeting the objectives of a nation-wide study commissioned by the NDA. It is recommended that readers also consult the other 2 reports, a comprehensive literature review of Irish and international literature on the challenges facing women with physical, sensory, mental health or intellectual disabilities in accessing health services during pregnancy, childbirth and early motherhood (Begley et al, 2009) and a presentation of findings 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 (Begley et al, 2010).

### 2. Purpose of review

The purpose of this review was to access, compile and analyse current policy governing procedure and practice in service provision at:-

- (i) Health Service Executive level,
- (ii) relevant professional body level,
- (iii) hospital/maternity unit level;

for women with disabilities who need to access publicly-funded Irish health services during pregnancy, childbirth and early motherhood, and to provide a commentary on policy development in this area in Ireland vis-à-vis the international situation.

### 3. Outline of review

The review sought to cover disability, health and gender-specific policies in Ireland and 9 other countries: United Kingdom (UK), the Netherlands, Sweden, Norway, Denmark, New Zealand (NZ), Australia, Canada and the United States of America



(USA). The UK and the last 4 countries were chosen as they are developed, English-speaking countries, and the remaining 4 provided a selection of EU member states regarded as leaders in social services.

A systematic search of the main databases and the libraries of Trinity College Dublin, the National Disability Authority and the Health Service Executive was undertaken to locate and identify current policies governing procedure and practice in service provision for women with physical, sensory and intellectual disabilities and mental health illness during pregnancy, childbirth and early motherhood. Consultation with social policy departments in Trinity College Dublin and University College Dublin was also undertaken and relevant departments and organisations in each of the countries identified above were contacted and consulted (Appendix 1).

One hundred and twenty-three (123) policies relating to disability, women's health and provision of health and/or maternity services and care, were sourced and retrieved. Three of these policies, the Royal College of Midwives (RCM) position paper on maternity care for women with disabilities (RCM, 2000), the Royal College of Nursing (RCN) guidelines for nurses and midwives on pregnancy and disabilities (RCN, 2007) and the Royal College of Obstetricians and Gynaecologists (RCOG) standards for maternity care (RCOG, 2008), referred specifically to and considered women with disabilities within the context of maternity care. These policies are all from the UK.

The legislation for each country was examined first, then any published disability strategies were perused and, finally, all relevant policy and guideline documents were reviewed and compared with the Irish policies and guidelines. A modification of the Walt and Gilson policy analysis model (1994) (Appendix 2) was used to conduct a systematic analysis of the policies.

## 4. Key research findings

The key findings from this review were:

#### **4.1. Findings in relation to disability legislation**

- Legislation protecting the rights of people with disabilities exists in Ireland and in the other 9 countries studied;
- The stimulus for all international legislation and policies was the United Nations Universal Declaration of Human Rights in 1948 (UN, 1948), leading to the development of the United Nations Convention on the Rights of Persons with Disabilities in 2006 (UN, 2006);
- At European level, the EU Disability Action Plan (2003-2010) sets out measures for member states with regard to equal opportunities for people with disabilities and, in particular, the Council of Europe Disability Action Plan (2006-2015) specifies action to be taken with regard to access to maternity services for women with disabilities.

#### **4.2. Findings in relation to Irish developments in the care of women with disabilities during pregnancy, childbirth and early motherhood**

- There are no specific Health Service Executive policies documented for the provision of maternity care for women with disabilities;
- The Commission on the Status of People with Disabilities acknowledged that women with disabilities were discriminated against, and were often perceived as asexual;
- No national policies relate specifically to women with disabilities who wish to access maternity services, but some recommendations contained within other health policies and strategies are applicable;
- The Disability Act requires the Department of Health and Children, as with other public bodies, to ensure that its services are accessible to people with disabilities, and to deliver an integrated service to people with and without disabilities where that is practical and appropriate. The Department has a statutory action plan on disability (Sectoral Plan), which it is currently reviewing on an annual basis;
- No guidance is provided by the 2 professional regulatory bodies (An Bord Altranais (the Irish Nursing Board) and the Medical Council) or the 2 bodies responsible for further medical education (the Irish College of General

- Practitioners and the Royal College of Physicians of Ireland) on the care of women with disabilities when accessing maternity services;
- A survey of all publicly-funded maternity units (n=19) in the country found that only one unit had a written policy governing practice and procedure in service provision for women with disabilities when accessing their services;
  - Maternity services tend to be more reactive than proactive and the provision of services is curtailed by financial, infrastructural and human resource barriers.

#### **4.3. Findings in relation to international policies relating to the care of women with disabilities during pregnancy, childbirth and early motherhood**

The findings in this section are based on a review of policies in the following 9 countries - the United Kingdom (UK), the Netherlands, Sweden, Norway, Denmark, New Zealand (NZ), Australia, Canada and the United States of America (USA).

- According to the documentation studied, the UK appeared to have the most developed strategy for women with disabilities, and for their maternity care, including a specific reference to women with disabilities in the Disability Discrimination Act (UK Parliament, 1995; 2005a);
- The UK has a comprehensive range of detailed policies and professional guideline documents on maternity services for women with disabilities;
- New Zealand and Australia had disability strategies but there is no particular focus on women in either strategy;
- Policy documents in New Zealand and Australia promote the improvement of women's mental, sexual and reproductive health and emphasise the importance of providing accessible health information and services for women with disabilities;
- None of the other 6 countries reviewed had a formal disability strategy;
- 3 countries (Canada, Australia and New Zealand) had a national women's strategy but only 2, of the strategies, Australia and New Zealand, referred to women with disabilities;

- The professional bodies in the UK have developed an agreed set of national standards for maternity care (RCOG, 2008), which is the only document from all countries reviewed that considers women with disabilities in the context of maternity care;
- Canadian policies acknowledge how women with disabilities are disadvantaged and doubly discriminated against on the basis of gender and disability, but do not address their specific needs;
- Although there is comprehensive disability legislation in the USA and a number of strategy and policy documents on disability, there is no national strategy addressing specifically the needs of women with disabilities during pregnancy, childbirth and early motherhood;
- The Netherlands, Norway, Denmark and Sweden have little or no published disability policies on women with disabilities availing of maternity services;
- Ireland compares well with other countries in terms of sufficient legislation, a National Disability Strategy (Government of Ireland, 2004b), the conduct of reviews of services for people with disability, and the existence of a designated body such as the National Disability Authority;
- There is a need, however, for improvements in policy development for the provision of maternity care services in Ireland for women with disabilities at national, professional body and local maternity hospital/unit levels.

## 5. Conclusion

The National Disability Authority and National Women's Council of Ireland have identified a need to explore access to reproductive and sexual health services for women with disabilities in Ireland, and have emphasised the importance of training and education in disability awareness for health professionals (NWCI, 2001; NDA, 2007). This review of national policies in 10 countries demonstrated that, with the exception of the UK, all countries lacked definitive policies relating to the care of women with disabilities when accessing maternity care. The lack of Irish policies highlights the importance of the National Disability Authority study, exploring the experiences of women with disabilities as they access the publicly-funded health services during pregnancy, childbirth and early motherhood.

## 6. Recommendations

### 1. For the Department of Health and Children

It is recommended that:

- Future revisions of the Sectoral Plan should include more detailed information concerning service provision for women with disabilities when accessing services in pregnancy, childbirth and early motherhood.

### 2. For the Health Service Executive

It is recommended that:

- Maternity hospitals and domiciliary midwifery services should have the skilled staff, facilities and service practices to enable them to deliver a quality service to women with disabilities during pregnancy, childbirth and early motherhood. This will require appropriate training for the relevant staff, clinical and non-clinical, in the care of women with disabilities;
- National policies, guidelines and standards be developed, encapsulating core provisions that will impact positively on procedure and practice in service provision for women with disabilities accessing health services in Ireland during pregnancy, childbirth and early motherhood. This should include guidance and standards on accessible facilities and specialised equipment where necessary to ensure quality service provision.

Appendix 6 sets out an example of a 'best practice' guideline, which evolved from the policy review process and is a compilation of a number of sources describing service provision for women with disabilities during pregnancy, childbirth and early motherhood in the UK. The content therein is modified from the 3 professional guidance documents (RCM, 2000; RCN, 2007; RCOG, 2008), which are, in turn, informed by clinical guidance documents produced by the National Institute for Health and Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN).

### 3. For professional bodies

It is recommended that:

- A collaborative guideline be issued to guide clinicians in best practice when caring for women with disabilities during pregnancy, childbirth and early motherhood. An example of a 'best practice' guideline is included in Appendix 6;
- The content of education programmes leading to registration as a health professional be amended to include reference to the maternity care needs of women with disabilities.

### 4. For maternity hospitals/units

It is recommended that:

- A written policy be developed to guide practice when caring for women with a physical, sensory or intellectual disability or mental health illness during pregnancy, childbirth and early motherhood. An example of such a 'best practice' guideline is included in Appendix 6;
- A review of the physical infrastructure of each unit be undertaken and buildings and facilities upgraded to provide accessible and suitable services for women with disabilities;
- An existing member of staff be designated as a disability officer in each maternity hospital or unit to oversee developments in relation to the care of women with disabilities and to provide advice and guidance to staff;
- Education and training be provided for both clinical and non-clinical staff in the care of women with disabilities;
- Standardised information booklets in appropriate formats, suitable for women with a physical, sensory or intellectual disability or mental health illness, be developed through collaboration with all maternity units and consultation with voluntary and non-voluntary disability organisations;
- The mental health education provided for both healthcare professionals and women focuses on other mental health difficulties, in addition to pre and postnatal depression;

- In line with the Code of Practice for Accessible Public Services, it should be ensured that information is made available to pregnant women with disabilities in the formats they require;
- All maternity units review their policies on the acceptance of guide dogs in main hospital areas and adapt them in line with best practice.

In all of the above, the views of women with disabilities should be sought, and utilised, in the development of policies, guidelines and services.

## 5. For clinicians

It is recommended that:

- In the absence of national guidelines, all clinicians become familiar with, and use, the guidelines relating to the maternity care of women with disabilities produced by UK bodies such as the National Institute for Health and Clinical Excellence and the Royal College of Obstetricians and Gynaecologists; an example of a 'best practice' guideline is also included in Appendix 6;
- Clinicians be alert to the possible presence of a mental health condition (of which depression is only one possibility);
- Clinicians develop individual care plans addressing specific needs of all women, including women with disabilities.



## Chapter One: Introduction and methodology of review

### 1.1. 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 comprehensive information on social policies, relating to disability and childbirth, both in Ireland and internationally. The review is one of 3 documents meeting the objectives of a nation-wide study commissioned by the NDA. It is recommended that readers also consult the other 2 reports, a comprehensive literature review of Irish and international literature on the challenges facing women with physical, sensory, mental health or intellectual disabilities in accessing health services during pregnancy, childbirth and early motherhood (Begley et al, 2009) and a presentation of findings 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 (Begley et al, 2010).

### 1.2. Purpose of review

The purpose of this review was to access, compile and analyse current policy governing procedure and practice in service provision at:-

- (iv) Health Service Executive level,
- (v) relevant professional body level,
- (vi) hospital/maternity unit level;

for women with disabilities who need to access publicly-funded Irish health services during pregnancy, childbirth and early motherhood, and to provide a commentary on policy development in this area in Ireland vis-à-vis the international situation.

### 1.3. Definition of “policy”

“Policy” is a broad, multidimensional concept, which sets out objectives that, when achieved, have positive outcomes for the population and/or organisation concerned. Policies and guidelines both express standards that have emerged or developed through a consensus, but guidelines are advisory in nature, whereas policies are considered a standard that should be followed. Policies can be classified into substantive and administrative policies (Torjman, 2005). Substantive policy refers to legislation, programmes and practices that govern clinical practice and service provision, and administrative policy refers largely to administrative practices. These 2 policies can be classified further into vertical or horizontal policies (Torjman, 2005). Policy that is developed locally, within or by an organisation that has the responsibility for implementing the policy, is known as a vertical policy. Horizontal policy is an integrated document developed by 2 or more organisations (or from a collaboration of units within an organisation), where each will mandate over a specific aspect of the policy. Policy can be further classified as reactive and proactive. Reactive, as the term suggests, is reacting or responding to circumstances, situations and crises where a policy or policies are introduced retrospectively. In contrast, proactive policies provide for a perceived eventuality where policies are put in place prospectively (Torjman, 2005).

### 1.4. Methodology

The review sought to cover disability, health and gender-specific policies in Ireland and 9 other countries: the United Kingdom (UK), New Zealand (NZ); Australia; Canada; the United States of America (USA); the Netherlands; Norway; Denmark and Sweden. A systematic search was undertaken to locate and identify current policies governing procedure and practice in service provision for women with physical, sensory and intellectual disabilities and mental health illness during pregnancy, childbirth and early motherhood. A web based search was undertaken and a number of methods were used to identify the relevant policies:

- database searches on Pubmed, CINAHL, PsychoInfo, PsychoArticle, Embase, Science Direct, Applied Social Science Index and Abstracts

(1983-2008), Social Science Citation Index and Social Sciences Index (1983–2008), Web of Science, Wiley inter science, Index to Theses;

- the library of Trinity College Dublin, the National Disability Authority and the Health Service Executive were searched for relevant policies, reports and general articles;
- a web based search on disability policy and health services in all of the countries identified in the introduction was conducted;
- a general internet search using Google and Google Scholar search engine and
- consultation with social policy departments in Trinity College Dublin and University College Dublin.

A general search was conducted using the following terms: access "health services" (women with a disability OR women with disabilities) (pregnancy OR prenatal OR antenatal OR childbirth OR early motherhood) (policy OR policies). A country-specific search was then conducted using the above terms in conjunction with the country name, using the 10 countries listed above. In addition to searching for "United Kingdom" the search term (Northern Ireland OR Scotland OR Wales OR England) was also used.

Relevant departments and organisations in each of the countries identified above were also contacted and consulted (see Appendix 1). Once identified and sourced, the policies were then retrieved and analysed. A modification of the Walt and Gilson policy analysis model (1994) (see Appendix 2) was the framework used to conduct a systematic analysis of the policies. When developing their analytical model, Walt and Gilson considered the work of many scientists. The model does not subscribe to the traditional rationalism and behaviouralism approaches to policy analysis; rather, it considers the importance of policy content, context, and process and the role of actors (or interest groups) in policy formulation and implementation.

## 1.5. Number of policies selected

One hundred and twenty-three (123) policies were sourced and retrieved. These policies related to 3 areas - disability, women's health and provision of health and/or maternity services and care. The policies were initially reviewed for appropriateness to the subject area and the provisions therein were reviewed for applicability to women with disabilities. Three of the policies retrieved, the Royal College of Midwives position paper on maternity care for women with disabilities (RCM, 2000), the Royal College of Nursing guidelines for nurses and midwives on pregnancy and disabilities (RCN, 2007) and the Royal College of Obstetricians and Gynaecologists standards for maternity care (RCOG, 2008), all from the UK, referred specifically to and considered women with disabilities. The remaining policies were reviewed and analysed for any relevant provisions that, when applied, have the potential to impact on service provision for women with any disability when accessing publicly-funded healthcare services during pregnancy, childbirth and early motherhood.

## 1.6. Format of the review

Chapter 1 introduces the review, sets out the 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 disability in Ireland, and an historical background of policies and Acts relating to the different disabilities. Chapters 3 and 4 identify and discuss the current policies that govern procedure and practice in service provision at HSE level and relevant professional or academic body level, respectively. Chapter 5 presents the results of a telephone survey of all 19 publicly-funded maternity hospitals/units in Ireland, to ascertain up-to-date information on their local policies and procedures relating to the care of women with disabilities. A summary of key findings concludes each of these chapters. In Chapter 6, identified international policies are compared with the Irish situation. Chapter 7 provides a summary overview, lists the main policy deficiencies, and makes recommendations for future development of services and research.

## **Chapter Two – Background and context of Irish disability policy**

### **2.1. Introduction**

A characteristic of most democratic states is that citizens are held to be 'equal before the law' (Government of Ireland, 2004a:40, 31) and that their fundamental rights will be respected, defended and vindicated. It is upon such values and beliefs that the United Nations Universal Declaration of Human Rights was made in 1948 (UN,1948). The United Nations appended this charter with further declarations in respect of the rights of disabled (UN, 1975) and intellectually disabled persons (UN, 1971). Recognising and charting the rights of people with disabilities has led to the development of many instruments, including the UN Standard Rules on Equalisation of Opportunities for People with Disabilities (UN, 1993) and, more recently, the UN Convention on the Rights of People with Disabilities (UN, 2006). These documents have promoted the development of disability-specific policies at national level, which act as the framework for the realisation of people's rights.

### **2.2. Global disability policy: United Nations Standard Rules**

The UN Standard Rules on the Equalisation of Opportunities for People with Disabilities (UN, 1993) was adopted by the General Assembly in resolution 48/96 of 20 December 1993. This instrument consists of 22 rules, which cover all aspects of life for people with disabilities. The rules are not legally binding but they are a tool for policy-makers and represent a political commitment by governments to take action to attain equalisation of opportunities for people with disabilities. The UN General Assembly identified accessibility as a priority in promoting equalisation of opportunities. It suggested that focusing on accessibility is an effective approach to reversing exclusion and enhancing equalisation of opportunities in a positive and sustainable way and Rule 5 considers "accessibility" with reference both to the physical environment and to information and communications services.

## **2.3. Global disability policy: United Nations Convention on the Rights of Persons with Disabilities**

### **2.3.1. The development of the Convention**

The drafting of a thematic convention for people with disabilities was first suggested in 1987 and a draft outline of a convention was prepared and submitted to the United Nations General Assembly. In November 2001, the Third Committee of the United Nations General Assembly expressed support for a convention subject to the recommendations of the Commission on Human Rights and the Commission for Social Development. The Commission on Human Rights and the Commission for Social Development endorsed the concept and, in December 2001, the United Nations established an ad hoc committee to consider the concept of developing a comprehensive instrument that would promote and protect the rights of people with disabilities.

Following numerous meetings over the next 5 years, the Convention on the Rights of Persons with Disabilities was drafted and accepted by the 8<sup>th</sup> General Assembly in December 2006. Ireland became a signatory state to the convention in March 2007 but, in order for it to be established it required ratification by 20 countries (Article 45). The Convention finally came into force in May 2008, after the 20<sup>th</sup> country ratified it. The Convention contains 50 articles and an optional protocol. It is founded on the principles of respect for dignity, non discrimination, inclusion and participation, recognition and respect for diversity, equality and accessibility. Article 8 is a significant provision that obliges signatory states to undertake 'immediate, effective and appropriate measures' (UN, 2006:17) to raise awareness regarding persons with disabilities, to combat prejudices relating to, and to promote recognition of, people with disabilities.

### **2.3.2. Accessibility of services to people with disabilities**

The issue of accessibility is addressed in Article 9 of United Nations Convention on the Rights of People with Disabilities, which decrees that states must take appropriate action to ensure that people with disabilities have access to the physical

environment, to transportation, to appropriate methods of communication and to information, including information on other services. Information must be provided in accessible and appropriate formats, suitable for people with all disabilities. Service providers are obliged to accept and facilitate the use of alternative methods of communication including sign language and Braille (UN, 2006: Article 9).

### **2.3.3. Rights of people with disabilities to health services**

Health is the subject of Article 25. Within this article, state parties must ensure that people with disabilities are afforded the same range, quality and standard of healthcare, either publicly or privately funded, as non disabled people. Proximity of health services is crucial to provision of care, and a recommendation of this article is that services are located as close as possible to the individual.

### **2.3.4. Implementation of the Convention**

Monitoring of states' responsibility is similar to other United Nation instruments – a Committee on the Rights of the Person with Disabilities will be established (Article 34-37) and states will be requested to submit periodic reports (Article 35). In addition to state reports individuals can also submit a report to a Committee on the Rights of the Person with Disabilities. At the time of publication, a number of measures have been enacted by Ireland, the United Kingdom, Sweden and the Netherlands to implement the Convention. In Ireland, an interdepartmental committee was established in 2007 to monitor the implementation of the legislative and administrative changes required by government departments in order to ratify the Convention. The interdepartmental group is reviewing the changes needed to implement the Convention. The UK has completed a review of all their existing policies and practices to ensure compatibility with the Convention. The UK government are currently considering the findings of this review and will then decide on ratification. In Sweden, a review to determine compatibility with existing legislation and policy was completed earlier this year. Ratification of the Convention requires a parliamentary resolution and the Swedish government expect a resolution on ratification by the end of this year. Ratification of the Convention is a more complex process in the Netherlands, and legislation may be required.



## 2.4. Global policy on disability/equality for women

### 2.4.1. United Nations Convention on the Elimination of All Forms of Discrimination Against Women

The UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) was adopted in 1979 by the UN General Assembly. Proponents of the Convention often refer to it as a bill of rights for women. The Convention defines discrimination against women as

*"...any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field" (UN, 1979: Article 1)*

Signatory states commit to undertake all appropriate measures to end all forms of discrimination against women by persons or institutions including incorporating the principle of equality and adopting legislation prohibiting discrimination against women so that women can enjoy all their human rights and fundamental freedoms.

The Convention is an instrument for the realisation of equality between men and women achieved by ensuring women have equal access to and opportunities in every spectrum of society. Article 12 of the Convention reaffirms the reproductive rights of women. State parties are obliged to undertake measures that ensure access to healthcare for women including access to appropriate services provided free of charge if necessary during pregnancy, childbirth and the postnatal period.

Countries that have ratified or acceded to the Convention also commit to submitting national reports at least every 4 years, which outline the measures each country has taken in compliance with their obligations ascribed within the convention. The CEDAW Committee requested state parties to submit specific information on women with disabilities in their periodic reports. The submission should include information on the measures taken by state parties to ensure social inclusiveness and equality in access to health services, education, employment and social security. Ireland's last

submission, the combined fourth and fifth periodic report to the Committee on the Elimination of Discrimination against Women, outlines how a policy of mainstreaming facilitates the inclusion of women with disabilities in all sectors of society. The report also outlines a number of initiatives to advance the rights of women with disabilities including the establishment of the National Disability Authority. It outlines the Authority's role in implementing and maintaining good standards in the provision of services for people with disabilities. Together with the Department of Justice, Equality and Law Reform, the NDA will *'monitor, guide and audit the progress made by government departments and agencies'* (Government of Ireland, 2003:18) including compliance with their responsibility in relation to accessibility (Government of Ireland, 2003). Information on the extent to which these measures are promoting the advancement of women's rights and the actual impact the measures have are not discussed (IHRC, 2003).

#### **2.4.2 United Nations International Conference on Population and Development, Cairo 1994**

The United Nations Economic and Social Council passed a Resolution in 1989 to hold an International Conference on Population and Development (ICPD) to discuss population issues. This conference was held in Cairo in 1994 and the agreed Programme of Action contained a number of aspects of relevance to this review. In the area of women's equality, an action point noted that governments should assist women to establish and realise their rights, and that these rights included those relating to reproductive and sexual health (UN, 1994). Two further action points of relevance concerned the recommendation that governments should ensure that all people have access to basic health-care services and should ensure community participation in health policy planning, and those with disabilities are mentioned as one of the groups to be included.

#### **2.4.3. United Nations Fourth World Conference on Women, Beijing 1995**

The Fourth World Conference on Women, held in Beijing in 1995, impacted significantly on the achievement of equality for women within their country of residence. A major outcome of the conference was the development of the Beijing

Declaration and Platform for Action, which identified 12 areas warranting attention, and 5 strategic objectives, each one accompanied by a list of actions. One area was the inequalities, inadequacies in and access to healthcare and related services (UN, 2000). Agreeing to accept the content of the Beijing Declaration and Platform for Action, governments committed to increasing women's access to appropriate, affordable and quality healthcare, information and related services throughout their life cycles. In order to achieve this objective, governments must reaffirm, protect and promote the attainment of a woman's right to the highest standards of physical and mental health and to incorporate this right into national legislation, health legislation and policies that reflect a commitment to women's health. It is emphasised that gender sensitive health programmes that address the needs of women, including women with disabilities, should be designed and implemented in cooperation with women and community based organisations.

Such measures may include the decentralisation of health services, the provision of accessible, available and affordable primary healthcare services, including sexual and reproductive healthcare. Governments also committed to strengthening and reorienting healthcare services, including reproductive healthcare, in order that universal access is achieved for all women as soon as possible and no later than 2015. With regard to women with disabilities, governments have committed to ensure that girls and women of all ages with any form of disability receive supportive services. Governments have undertaken to support, involve, collaborate and cooperate with voluntary and non-voluntary organisations in policy making, designing, planning and implementing health and related services. Mental health services are to be integrated into primary care settings. Governments have committed to preparing and disseminating accessible information through a variety of mediums including public health campaigns, the media and the education system in order that women acquire knowledge about their health, sexuality and reproduction.

In May 2000 the United Nations General Assembly reviewed progress in implementing the content of the Beijing Declaration and Platform for Action and adopted a resolution, which identified further actions and initiatives to facilitate the implementation of the programme. It reiterates the principal of universality and the

necessity to adopt, enact, review and revise health legislation, policies and programmes in collaboration and cooperation with women's organisations. The allocation of necessary budgetary resources is recommended to ensure the highest standard of attainable physical and mental health in order that all women, including women with disabilities, have full and equal access to healthcare, information and services throughout their life span. Ten years following the inception of the programme, government representatives attended the 49<sup>th</sup> session of the Commission on the Status of Women in New York and reaffirmed the commitment to implement the content of the Beijing Declaration and Platform for Action in its totality.

## **2.5. Disability policy in Europe**

### **2.5.1. General disability policy**

The Council of Europe has advanced disability policy, which has evolved and developed over the past 2 decades. The first conference of ministers with responsibility for advancing policies for people with disabilities occurred in 1992, and recommended the development of a policy for people with disability. The ministers convened for their second conference in May 2003, with the objective of developing principles that would form the pillars of future disability policy and public service provision for member states. The ministers, on conclusion of proceedings, adopted the Malaga Ministerial Declaration on People with Disabilities: 'progressing towards full participation as citizens' (Malaga Ministerial Declaration on People with Disabilities, 2003). The ultimate aim of this declaration was to improve the quality of life of people with disabilities. Emphasis was placed on the concept of integration and full participation of people with disabilities in order to promote the elimination of all forms of discrimination against them. To achieve the aim, a European Disability Action Plan was to be devised. Subsequently the Council of Europe Disability Action Plan (2006-2015) (Council of Europe, 2006) was developed. The plan provides a framework to which policy makers in member states can refer when designing, implementing and evaluating disability policies and strategies. The plan consists of 15 action lines/points that cover the person's life span, which essentially are the objectives of the plan. Action line 6 makes reference to the built environment and action line 9 refers to healthcare.

Under the provisions of action line 6, member states are obliged to ensure that all policies embrace the principle of accessibility and consideration be given to a barrier-free built environment. Guidelines and standards are to be developed to promote accessibility and the use of devices and technologies to improve accessibility must be promoted. Referring to healthcare, action plan 9 establishes that all people with disabilities, regardless of age, gender or impairment have equal access to healthcare services including access to specialised services if required. It determines that women with disabilities should have equal access to antenatal, family planning advice and gynaecological services and care. To overcome prejudicial attitudes the action plan advocates that disability awareness and training becomes integrated into health professional training and professional development programmes. The plan recognises specific groups that require a cross-cutting response across all the Plan's actions including, specifically, women and girls with disabilities. It states required action "extends across a broad range of areas including relationships, parenthood, family life, sexuality etc." (Council of Europe, 2006).

The EU Disability Action Plan (DAP) 2003 - 2012 issued by the European Commission aims to promote equal opportunities for people with disabilities throughout the EU member states by ensuring that disability issues are integrated within all relevant EU policies. The DAP is developed in 2 year phases; the 2008-2009 DAP focuses on accessibility and aims to "stimulate inclusive participation of people with disabilities and to work towards full enjoyment of fundamental rights." According to the Commission this is done through "fostering accessibility of the labour market; boosting accessibility of goods, services and infrastructures; consolidating the Commission's capacity to support accessibility through research; facilitating the implementation of the UN Convention; and complementing the Community legislative framework of protection against discrimination" (Council of Europe, 2008).

### **2.5.2. National perinatal/maternity mental health policies**

The development of national policies and funding for mental health services and innovations across Europe as a whole has not kept pace with developments in the

general disability field. In addition, some initiatives that are introduced overlook the wide psychosocial impact of diverse mental disorders (Knapp et al, 2007). In 2005, the World Health Organisation (WHO) recommended the routine assessment of the mental health of new mothers by obstetricians and health visitors with the provision of interventions as necessary. They stated that specialist services should be developed across Europe in order to address gender specific issues. The need to raise the awareness of healthcare staff about their own attitudes towards suicide and mental health difficulties was also stressed (WHO, 2005).

In 2004, the European Forum of National Nursing and Midwifery Associations and the World Health Organisation presented a statement on mental health at the WHO European Ministerial Conference on Mental Health (European Forum of National Nursing and Midwifery Associations, 2004). The statement emphasised the contribution that nurses and midwives could make towards reducing stigma and discrimination against people with mental disorders, thus minimising its effect on nursing care. The need to increase the development of continuity of care and collaboration across nursing and midwifery professions was stressed together with a requirement to recruit and retain nurses and midwives with mental health skills. Another element of the statement observed that general nursing and midwifery education programmes do not necessarily prepare nurses and midwives to be responsive to the mental health needs of patients or clients, thus the mental health course components of nurse education programmes should be strengthened. The forum also supported the development of specialist mental health training for nurses and midwives.

The Association of European Psychiatrists is moving towards integration and harmony but currently there are no cohesive policies across Europe on perinatal mental health care. According to Cox (2007), health visitors<sup>1</sup> are only found in the United Kingdom, and child psychiatrists (rather than adult) are responsible for mother and baby units in France. The Marcé society, an international society for the

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<sup>1</sup> A highly qualified nurse or midwife whose remit is to assess the health needs of families and individuals out in the community. They offer practical help and advice in order to promote health and prevent illness in community settings.

understanding, prevention and treatment of mental illness related to childbearing, has developed a checklist of standards for mother and baby units (Glangeaud-Freudenthal and Barnett, 2004).

## 2.6. Health reform in Ireland

Over the past 5 years the Irish healthcare system has undergone a series of unprecedented health reforms. To achieve the 4 national goals set out in the Health Strategy, Quality and Fairness – A Health System for You (Department of Health and Children, 2001a) the government announced a health reform programme in June 2003. The health strategy identified that in order to enhance the provision of healthcare in Ireland changes were required and it recommended an examination of the organisational structures and strengthening of primary care. Subsequently several reports (the Prospectus Report, Brennan Report and Hanly Report) were commissioned. These reports were charged with examining the organisational structure and the funding of the health and acute hospital system. Collectively these reports suggested that there was a need for significant reform of the health services and that there was scope to improve the efficiency and productivity of the system.

The proposed health reform programme was designed ultimately to improve health service delivery and to guarantee consistent national, regional and local patient-centred care in a co-ordinated and integrated manner. Several reforms were proposed; among them was the rationalisation of health service agencies, including consolidation and amalgamation of existing agencies, the abolition of the regional health board structures and the establishment of a Health Service Executive that would facilitate the management and delivery of the health service in a comprehensive and rational way. The health reform programme was to alter the organisation of the health service in Ireland significantly. The development of 3 core units within the new HSE was proposed – including the development of an interim National Hospitals Office, which would oversee the reform of the hospital sector, the development of a Primary, Community and Continuing Directorate, which would have responsibility for non hospital services and the development of the National Shared Service Care Centre. At the time of writing, there are some suggestions that under



current Health Service Executive reforms the Primary, Community and Continuing Directorate may be abolished. Within the provisions of the reform programme, the Department of Health and Children were devolved of their responsibility to manage and deliver health services; instead, they were to adopt a more strategic position with responsibility for policy development, overseeing and evaluating service delivery. The establishment of an authority to monitor and ensure the provision of quality and effective care was also recommended.

The Health Information and Quality Authority (HIQA) was established under the Health Act 2007 (Government of Ireland, 2007c) with the primary objective of monitoring and ensuring the provision of quality and effective care. This will be achieved by devising, implementing and auditing national standards for the provision of health and social care, with the exception of mental health services. The standards will be informed by evidence and best practice both nationally and internationally and will reflect the minimum standards for quality and safety. With respect to people with physical and intellectual disabilities, HIQA devised standards pertaining to the independent assessment of needs (HIQA, 2007) and, in May 2009, standards in relation to residential services for people with disabilities were published (HIQA, 2009).

## **2.7. Disability policy in Ireland**

### **2.7.1. Development of policies for people with disabilities**

The UN Standard Rules on the Equalization of Opportunities for People with Disabilities was the springboard for action, highlighting as it did the plight of people with disabilities, who were clearly seen to be at risk of having their rights denied or ignored at the level of social policy making. This was the experience of persons with disabilities in Ireland during the 1990s (Government of Ireland, 1996) and led to the development of new policies, supported by disability and equality legislation.

### **2.7.2. The Commission on the Status of People with Disabilities (1996)**

In 1993 the Irish government established the Commission on the Status of People with Disabilities, which was tasked with the responsibility to record and document what contemporary life in Ireland was like for people with disabilities. Various mechanisms including submissions, consultations, interviews and focus groups were used to collect information. Contributors identified how society excluded them from 'every aspect of economic, social, political and economic life' (Government of Ireland, 1996:4). People with disabilities called for equality and the opportunity to participate fully in an equal society, which was at that time hindered by the lack of access to appropriate services such as transport. This lack of accessible and appropriate transport means that people with disability may not have full access to essential services such as employment, education and training and health. Health services were described as fragmented with no coordination between service providers. Information about the services was not available in any accessible format, which became a further mechanism to isolate and marginalise people with disabilities. The Commission presented a number of recommendations on the basis of 3 guiding principles - equity, maximising participation and enabling independence and choice. The Commission was confident that these guiding principles would facilitate the full and equal participation of people with disabilities in Irish society. In doing so, people with disabilities will be afforded the opportunity to achieve their full potential and exercise their right to quality services that address their needs at all stages of their lifespan.

The Commission contended that people with disabilities have a basic and fundamental right to a health service that is accessible, equitable, person centred and responsive to their particular need, and to gain entry into and move freely within a building. Furthermore, the Commission acknowledged that women with disabilities were discriminated against, and marginalised, on the basis of their disability and gender. The Commission noted a general misperception that women with disabilities were asexual and, in an attempt to address this, the Commission identified how people with disabilities should be afforded the right to experience the same degree of fulfilment from relationships and sexuality as any other person in society.

### **2.7.3. A review of the provision of health and social services for people with physical and sensory disabilities**

On foot of the report of the Commission on the Status of People with Disabilities a review Group was established in 1996 by the Department of Health to examine the provision of health and personal social services for people with physical and sensory disabilities. Within their terms of reference the review group was to present recommendations on the development of services that would effectively meet the needs of this population. The report was the first detailed review into services for people with a physical and sensory disability and it was to become the blueprint for the development of future health services for this cohort. Many issues emerged from the consultation process including inadequate access to information about service provision and entitlements, inadequate transport services; inadequate provision of health services and inadequate co-ordination of services between the statutory and voluntary sectors, which resulted in fragmentation of service delivery (Department of Health, 1996).

Although the scope of the review was an examination of the health services, the group decided to focus on specific areas such as early assessment, rehabilitation and community support. This review of community support incorporated the general practitioner (GP) services and, while the review group acknowledged the input of resources to improve accessibility to services provided by GPs, they recommended that 'specific measures should be undertaken to ensure GP surgeries are accessible to people with disabilities' (Department of Health, 1996:47). The review also revealed that GPs and other health professionals lacked the expertise to communicate with people who were deaf or hard of hearing and identified how the resulting communication barriers could be overcome if communication support services such as sign language interpreters were employed. Health boards were tasked with the responsibility for improving the provision of integrated, coordinated and person centred communication support services. The group also recommended that the Department of Health should ensure that any publications from the Health Promotion Unit would be available in an accessible format for people who are deaf and hard of hearing. A similar recommendation was made for people who are blind or vision impaired.

Responding to the many submissions that identified the lack of co-ordination and the fragmentation of services, the group recommended local and national initiatives including the establishment of regional co-ordinating committees, the implementation of a process to evaluate the health services and the appointment of a Director of Services for people with a physical or sensory disability (Department of Health, 1996). The group also acknowledged the many social and personal benefits of an adequate and accessible transport system for this population. It recognised how access to public transport can help achieve independence and integration for such persons and recommended that steps be taken to ensure public transport is accessible to all people with disabilities (Department of Health, 1996).

#### **2.7.4. The establishment of the National Disability Authority (2000)**

The National Disability Authority was established in 2000, following a recommendation of the Commission on the Status of People with Disabilities. It is an independent statutory body whose principal function is to advise Government on disability policy and practice, in the context of Government policy that people with disabilities will be served by mainstream public services and policies. The NDA's mandate is set out in the National Disability Act 1999 and the Disability Act 2005 and, in summary, is:

- To provide policy advice to Government and public bodies
- To assist the Minister with responsibility for disability in the co-ordination and development of policy in relation to persons with disabilities
- To undertake, commission and collaborate in disability research and assist in the development of statistical information
- To advise on standards and guidelines in services to people with disabilities
- To develop standards, education and promote awareness of Universal Design.

One of the studies commissioned by the NDA mapped the range of service provision for people with disabilities in Ireland (Pillinger, 2004). The study was undertaken at a time of considerable and significant change in health policy and organisational reform. The second national health strategy – Quality and Fairness: A Health System

for You (DOHC, 2001a) and the Health Reform Programme (DOHC, 2003) were being implemented at the time, and it was envisaged that the policy and organisational changes would provide tremendous opportunity to introduce, develop and realise policies that would ensure the mainstreaming of services in an equal and fair manner for people with disabilities. The information that emerged from the study provided evidence of the diversity that existed in the provision of disability and mental health services and highlighted the continual dominance of the medical model despite the calls from the disability sector to deliver services within the framework of a social model (Pillinger, 2004). This social model positions the person at the centre of care, promoting independent living with services that are community based, where the overarching principles of equality and non-discrimination are dominant. The study findings also identified a variation in the services provided to persons with a disability across regions and, generally, service provision was found to be inadequate and inappropriate for people with disabilities. Unfavourable attitudes were experienced by many people and concern was expressed about the lack of independent, transparent and quality advocacy services for people when using the health services. The study concluded with a number of recommendations, and suggests that services should be community based, co-ordinated and integrated and that, as people with disabilities have a vital part to play in the planning and monitoring of services, consultation should be an essential aspect of service planning and delivery (Pillinger, 2004).

## **2.8. Irish equality and disability legislation**

### **2.8.1. Introduction**

Government policy in Ireland has moved towards a social model of disability emphasising removal of the barriers to achieve inclusion and full citizenship, and away from a medical model that viewed individuals as dependent. In line with this, responsibility for disability issues now reaches every Government Department and the wider public service and is no longer confined to the health service. The Disability Act 2005 (Government of Ireland, 2005a), among other provisions, gives statutory force to this mainstream responsibility. The Government's broad-ranging National Disability Strategy, reaffirmed by the social partners in Towards 2016, sets out an agenda for every Government Department and public body, including detailed

statutory Sectoral Plans for 6 key Departments, and including the health service. Equality legislation has been enacted in Ireland to outlaw discrimination in the provision of goods and services, on a number of grounds, including disability, in the Equal Status Acts 2000 and 2004 (Government of Ireland, 2000, 2004d). Similar acts have been put in place in other countries including Canada (Canadian Department of Justice, 1985), the UK (UK Parliament, 1995) and New Zealand (New Zealand Ministry of Health, 2000a). Relevant equality legislation has also been enacted in the USA (United States Department of Justice, 1990). The role of these pieces of legislation has been to protect the rights of people with disabilities, and it is clear that they have been successful to some extent in this regard.

### **2.8.2. The Equal Status and Equality Acts**

Equality legislation plays an essential part in the accessing of mainstream services for people with disabilities. The Equal Status Act (Government of Ireland, 2000) obliges anyone providing a service, including the HSE, to accommodate the needs of people with disabilities provided that to do so does not incur more than a 'nominal cost'. The Act requires a person providing goods or services to do all that is reasonable to accommodate the needs of a person with a disability by providing special facilities or treatment. In 2004 the Act was amended, enacting 3 European directives on race, gender and employment into Irish Law. Subsequently a number of mainly procedural changes occurred and the Equality Act 2004 emerged (Government of Ireland, 2004d). The Act changed the definitions of direct or indirect discrimination, harassment, victimisation and reasonable accommodation and made a number of changes in relation to what is covered by equality law.

### **2.8.3. The Disability Act (2005)**

#### **2.8.3.1. Assessment of needs**

The Disability Act (Government of Ireland, 2005a) was launched with the fundamental objective of advancing the participation by people with disabilities in everyday life. Part 2 of the Act refers to the delivery of individual health, education and personal social services for people with disabilities. It establishes that people with disabilities have a statutory entitlement to an impartial independent assessment of needs (Sections 8-10). This provision is applicable to persons with a restriction

“permanent or likely to be permanent [which] results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes,” which gives rise to the need for services. The Disability Act also sets out provisions on the role of the needs assessment officers, and for liaison officers in the preparation of a service statement. The Act provides for complaints regarding the needs assessment and for an independent appeal process. Standards for this need assessment process have been developed through national consultation by the Health Information and Quality Authority. The standards seek to ensure that effective links with other services are established and state that "where assessment of need reports indicate a requirement for referral beyond the health and education sectors, guidelines and pathways for such referrals are in place" (HIQA, 2007).

### **2.8.3.2. Accessibility of public buildings**

Part 3 of the Disability Act 2005 sets out the legal obligations of public bodies to provide integrated and accessible public services to people with disabilities, to provide assistance to people with disabilities to access services, to provide accessible information, and to engage in procurement of accessible goods and services. These requirements apply subject to what would be practicable and appropriate. Each public body must have an Access Officer to provide for, arrange or co-ordinate the assistance to people with disabilities. There is a statutory Code of Practice for Accessible Public Services (2006), which covers services, information and procurement. Compliance with this Code of Practice is deemed to be compliance with the Act. There is also a legal obligation to ensure that by end-2015 the areas of their buildings used by the public are accessible for people with disabilities. The requirement is to become compliant with Part M of the Building Regulations (which deals with disability accessibility) by the end of 2015, or within 10 years of any revision to Part M which takes place after 2005. A proposed revision to Part M has gone to public consultation in mid-2009. If agreed by the end of 2009, this would require compliance with the new Part M standards (involving retrofitting these standards if necessary) by the end of 2019. Exemptions may apply to buildings in temporary use as public buildings, or where, having regard to the use to which the building is put, making it accessible to people with disabilities would not be justifiable on grounds of cost.

### **2.8.3.3. Appropriate and accessible communication**

In addition to accessibility to the built environment the Act also confers a statutory obligation on the HSE to ensure that all communication with any persons with a hearing or vision impairment, in as far as practicable, is provided in a form that is appropriate and accessible to the person concerned. The Health Service Executive and other health service providers that have the legal status of public bodies must satisfy these legal requirements. The statutory Sectoral Plan of the Department of Health and Children sets out proposals to improve the accessibility of mainstream health services.

## **2.8.4 The National Disability Strategy**

### **2.8.4.1. Introduction**

The National Disability Strategy, launched by the Government in autumn 2004, is a programme of co-ordinated actions across Government Departments to deliver on the agenda of including people with disabilities in the mainstream of Irish life. While it provides for improvements in the accessibility of health services and public services generally to people with disabilities, the Strategy does not specifically reference maternity services for people with disabilities.

The Programme for Government 2007-2012 sets out a number of other general commitments, which are of relevance. There is a commitment to deliver a fully modern woman-centred health service. Recommendations of the Women's Health Council (WHC 2005a, 2005b, 2007a, 2008) would be relevant in this respect. The Government programme has also committed to investing comprehensively in health-promoting activities and awareness campaigns. The Government programme also commits to prioritise the interests of people with disabilities, and to the National Disability Strategy.

### **2.8.4.2. The National Disability Strategy**

The National Disability Strategy has the following core elements:

- Disability Act 2005



- Education for Persons with Special Education Needs Act 2004 (EPSEN)
- Sectoral Plans on disability of 6 Government Departments, covering communications, employment, environment, health, social welfare and transport
- A multi-annual investment programme for high-priority disability services, which ran from 2005 to 2009
- Citizens Information Act 2007, providing for a personal advocacy service.

The National Disability Strategy builds on a foundation of equality legislation, which bars discrimination against people with disabilities in employment and in the provision of goods and services.

Structures and a reporting framework have been put in place to oversee the implementation of the National Disability Strategy. The Office for Disability and Mental Health, headed by a Minister of State, has a specific remit to develop cross-sectoral engagement across the Departments of Health and Children, Education and Science, Enterprise, Trade and Employment, and Justice, Equality and Law Reform.

The Sectoral Plan for the Department of Health and Children was approved by the Oireachtas in 2006, and reviewed at the end of 2007. There are specific commitments in relation to the appointment of a national specialist in accessibility by HSE, the designation of Access officers, disability awareness training, review of procurement policies, practices and procedures, guidance and protocols to ensure all client communications are accessible, and an audit of public buildings and facilities. These commitments would apply to maternity services as to other health services, but these are not specifically mentioned. The national specialist in accessibility had not yet been appointed by mid-2009.

#### **2.8.4.3. The social partnership agreement 'Towards 2016'**

The social partnership agreement 'Towards 2016' (Government of Ireland, 2006) sets out a strategic framework agreed by Government and the social partners to meet the economic and social challenges over the decade to 2016. The agreement adopts a lifecycle approach, building on the NESC report 'Developmental Welfare State'

(NESC, 2005) and 'places the individual at the centre of policy development and delivery' (Government of Ireland, 2006:6). Four lifecycle stages are identified: children, those of working age, older people, and people with disabilities.

Towards 2016 provides that the agreement's policies in relation to disability will be delivered via the National Disability Strategy, and it sets out goals under the National Disability Strategy for people with disabilities:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;
- Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services;
- Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;
- Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential;
- Carers would be acknowledged and supported in their caring role.

Whilst the strategy is grounded in recognition of the importance of assessing individuals' needs, it does not specifically speak to the reality of maternity needs for women with disabilities.

### **2.8.5. Related policies and legislation**

Related legislation such as the Criminal Law (Sexual Offences) Act 1993 in Ireland (Government of Ireland, 1993), similar to the Crimes Act 1961 in New Zealand (Government of New Zealand, 1961), essentially criminalises sexual activity for persons with intellectual disability, other than with one's spouse. This legal position, which stems from the protectionist view that such persons are unable to consent, may be a contributing factor to the absence of discussion in policy documents around intellectual disability and maternity services.

The Citizens Information Act (Government of Ireland, 2007a) provides for the establishment of a comprehensive advocacy service to support people with disabilities. This statutory personal advocate service has yet to be established. However the Department of Social and Family Affairs funds a range of disability advocacy models but, to date, none have covered the maternity area.

In September 2008, the Department of Justice, Equality and Law Reform published the Mental Capacity Scheme of Bill. The proposed legislation is significant in the process towards Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities. Article 12 of the Convention states that people with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life and State Parties to the Convention shall take appropriate measures to provide access by people with disabilities to the support they may require in exercising their legal capacity. The purpose of the proposed legislation is to reform the laws that protect adults who, due to illness, accident or intellectual disability, are unable to make decisions for themselves or exercise their legal capacity. The bill, which at the time of writing, is in development, has important implications for protecting the rights of those with cognitive and mental health impairments who may lack capacity to consent to medical treatment.

## 2.9. Summary

This chapter has provided the background and framework within which Irish policies may be viewed. The commencing point for international legislation and policies was the United Nations Universal Declaration of Human Rights in 1948 (UN, 1948), leading to the development of the United Nations Convention on the Rights of Persons with Disabilities in 2006 (UN, 2006). The articles in this convention cover the rights of people with all disabilities to information, access to the physical environment and to the same range, quality and standard of healthcare as non disabled people. All states that have signed the convention are requested to submit periodic reports of their compliance.

The Council of Europe developed a Disability Action Plan (2006-2015) (Council of Europe, 2006) that provides a framework for policy makers in member states to use when designing, implementing and evaluating disability policies and strategies. Strategies for women with mental health difficulties, such as the recommendation for routine assessment of the mental health of new mothers by obstetricians and health visitors, have been promoted (WHO, 2005). In particular, the contribution that nurses and midwives could make towards reducing stigma and discrimination against people with mental disorders has been highlighted (European Forum of National Nursing and Midwifery Associations, 2004).

In Ireland, considerable reform in the structure and organisation of the health service has taken place with the establishment of the Health Service Executive, the adoption of a more strategic, policy development position for the Department of Health and Children, and the establishment of the Health Information and Quality Authority to monitor and ensure the provision of quality and effective care. In the last 2 decades people with disabilities, who have had their rights denied or ignored at the level of social policy making in the past (Government of Ireland, 1996), have become involved in the development of new policies, supported by disability and equality legislation.

In 1996, the Irish government established the Commission on the Status of People with Disabilities, who presented a number of recommendations on the basis of 3 guiding principles - equity, maximising participation and enabling independence and choice. The Commission acknowledged that women with disabilities were discriminated against, and were often perceived as asexual. The implementation of a recommendation of the Commission led to the establishment, in 2000, of the National Disability Authority. In addition, a review group was set up, which reported on the main issues for people with disabilities, including inadequate access to information about service provision and entitlements, inadequate transport services; inadequate provision of health services and inadequate co-ordination of services between the statutory and voluntary sectors (Department of Health, 1996). Studies commissioned by the National Disability Authority have identified inadequate and inappropriate service provision for people with disabilities, unfavourable attitudes and a lack of

independent, transparent and quality advocacy services. The Government's commitment to mainstreaming of services for people with disabilities underpins the Disability Act 2005 and a range of specific measures to promote the inclusion of people with disabilities are set out in the sectoral plans of 6 government departments within the Disability Strategy. The Citizens Information Act (Government of Ireland, 2007a) also affords people with disabilities the right to apply for assignment of a personal advocate.

The following 3 chapters identify and discuss the current policies that govern procedure and practice in service provision in Ireland at HSE level, relevant professional body level and at the level of individual maternity hospitals or units.

## **Chapter Three: Current policies governing procedure and practice in service provision at Health Service Executive level**

### **3.1. Introduction**

The health service reform programme devolved the Department of Health and Children of their responsibility to manage and deliver health services. This responsibility was transferred to the Health Service Executive, and the Department of Health and Children adopted a more strategic position with responsibility to advise on the development of the health system including policy and legislation. The following section describes the establishment and development of the Health Service Executive and identifies and discusses the current policies that govern procedure and practice in service provision at Health Service Executive level in Ireland. In addition to the Disability Strategy and the legislation supporting it, 8 national policies are presented and discussed.

### **3.2. The establishment and development of the Health Service Executive**

#### **3.2.1. Services provided by the Health Service Executive**

Prior to the establishment of the Health Service Executive, regional Health Boards were charged with the responsibility of providing a range of health services for people with disabilities. Each Health Board was obliged to develop an annual service plan, which indicated how health services were to be planned and delivered for this population. When the health boards were dissolved this responsibility was transferred to, and assumed by, the Health Service Executive. The Health Service Executive, a pillar of the health reform programme, was established in 2005 under the provision of the Health Act 2004 (Government of Ireland, 2004e). It is responsible for the provision of health and personal social services that will improve, promote and protect the health and welfare of all persons living in the Republic of Ireland. The Health Service Executive provides a range of services specifically for people with

disabilities including health services and assessment, rehabilitation, community care and residential care. Some services are provided directly by the Health Service Executive while some of the community, residential and rehabilitative services are provided by voluntary organisations with funding from the Health Service Executive.

### **3.2.2. The Health Service Executive National Service Plans**

The Health Service Executive's National Service Plans (NSPs) for the preceding 3 years provides empirical evidence of the organisation's commitment to resource and develop services for people with disabilities. Each plan is governed by the philosophy of enabling each individual with a disability to achieve his/her full potential and maximise their independence. Service planning and delivery are underpinned by a population based approach, which recognises the various factors that affect a person's health and aims to promote and protect the health and wellbeing of all individuals and to reduce health inequalities (HSE, 2008). Provision of disability services were initially informed by the legislative framework of the Health Act 1947 and later by the health policy document Quality and Fairness – A Health System for You (Department of Health and Children, 2001a). Subsequent National Service Plans were informed by the provisions of the Health Act 2004, the National Disability Strategy (Government of Ireland, 2004b), which is underpinned by an equality framework and mandates for the mainstreaming of services for people with disabilities, and the Disability Act (Government of Ireland, 2005a).

Endorsing a population health approach ensures that disability services are needs-led, person-centred and underpinned by the principle of equality. In the 2008 National Service Plan (HSE, 2007), the HSE committed to enhancing services in the community by providing a local point of access for a range of health and social services. The Plan sets out the focus for the provision of care away from acute and institutional settings towards more appropriate and community-based settings. This is clearly documented in respect of people with intellectual disability. In addition to providing for the creation of 80 additional residential places per year the HSE committed to providing 250,000 additional hours of personal assistant/home support. These initiatives will be funded from the multi-annual investment programme which is an element of the National Disability Strategy. The Plan identifies how the

intellectual, physical and sensory databases would also be reconfigured in partnership with other key stakeholders, taking cognisance of the requirements of the Disability Act (2005). Information from both databases would inform the allocation of services and ensure services were delivered in response to identified need. In their National Service Plan 2009 the HSE proposes to employ new therapists to provide a range of services for people with disabilities; this action is set against a 1% reduction in the funding to voluntary disability providers (HSE, 2009a).

### **3.2.3. The Health Service Executive Transformation Programme (2007-2010)**

Embracing the culture of change that accompanied the health service reform programme and its own establishment, the HSE published its transformation programme (HSE, 2006), which was developed following consultation with staff working within the HSE and related agencies and establishes the organisation's mission and fundamental purpose. Three themes, 'easy access, public confidence and staff pride' (HSE, 2006:9) guide the programme, which identifies 6 priorities to be addressed during its life span.

Transformation of the national maternity services is one of the provisions of the programme, and this was reiterated in the National Service Plan 2008 (HSE, 2007). An Expert Advisory Group on Maternity Services was established to advise on the strategic development and implementation of operational policies for future maternity services. The first stage in this process involved an independent review of maternity and gynaecology services in the greater Dublin area, which has taken place, and the report was recently published (HSE, 2009b). The review was carried out by KPMG and a significant number of key stakeholders were engaged in the process. Current and future demands and the capacity within the system were considered (HSE, 2008). The report recommended an enlarged and improved service offering a choice of different models in a wide range of settings to include an increase in midwifery-led care, community midwifery services and a relocation of some parts of the current maternity services to outreach community and primary care settings. Although the review focused on the greater Dublin area, the report gave a commitment to look at an extension of this model nationwide (HSE, 2009b). The publication of this report



will provide a national framework to address infrastructure and workforce constraints, the development of a model of care, based on international best practice and the reconfiguration of maternity services. Although the needs of women with disability were not specifically mentioned, an increase in the provision of services at a community level will assist in meeting their needs for an accessible service.

### **3.3. General policies governing procedure and practice in service provision at Health Service Executive level**

#### **3.3.1. The development of national policy**

A search of the HSE library for current and archived policies governing practices for service provision for women with disabilities during pregnancy, childbirth and early motherhood identified that there are no specific policies developed in this area.

The HSE is the statutory provider of publicly-funded health services including maternity services. By virtue of the fact that the HSE are a public body, they are also obliged to fulfil their statutory requirements mandated in the provisions of the Disability Act (Government of Ireland, 2005a), which forms a core element of the National Disability Strategy (Government of Ireland, 2004b). The National Disability Strategy underpins the participation of people with disabilities in Irish society by building on existing policy and legislation including the policy of mainstreaming public services for people with disabilities. The development of disability policy was viewed primarily as the responsibility of the Department of Health and its agencies (Quin and Redmond, 2003) but the 1980s and 1990s witnessed the emergence of the concept of mainstreaming both at international and national level, and it was during this period that policy makers and service providers began to embrace the contention that to implement disability policy successfully, consultation and collaboration with policy makers in other government departments and voluntary organisations was essential. Equality and anti-discrimination legislation (detailed in Chapter 2) were the antecedent to current disability legislation and strategy.

In addition to the national disability strategy (Government of Ireland, 2004b), other policies in the area of health service provision, and women's health were sourced and reviewed. The policies that informed this review were:

- The National Health Strategy: Shaping a Healthier Future (Department of Health, 1994);
- A Plan for Women's Health (Department of Health, 1997);
- The National Health Promotion Strategy (Department of Health and Children, 2000);
- Quality and Fairness – A Health System for You (Department of Health and Children, 2001a);
- Primary Care: a new direction (Department of Health and Children, 2001b);
- A Vision for Change, the report of the expert group on mental health policy (Department of Health and Children, 2006a);
- The National Women's Strategy (2007-2016) (Department of Justice, Equality and Law Reform, 2007);
- The National Intercultural Health Strategy (2007-2012) (HSE, 2008).

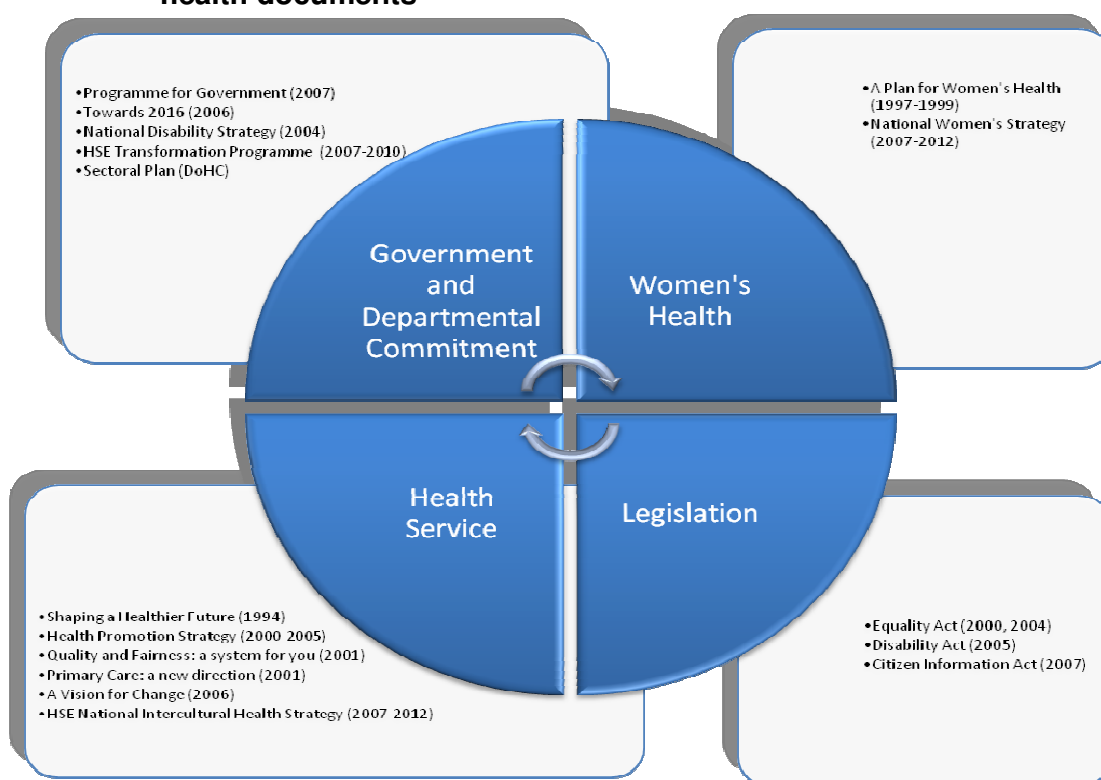
Again, no single specific policy focused on the provision of health services for women with disabilities during pregnancy, childbirth and early motherhood; however, some provisions of the reviewed policies are applicable. Figure 1 depicts the various legislative, governmental, health service and women's health documents that are included in this review.

### **3.3.2. The National Health Strategy - Shaping a Healthier Future**

In April 1994 the Minister for Health published the first ever National Health Strategy (Department of Health, 1994). Underpinned by 3 principles - equity, quality of service and accountability - the focus was on 2 outcomes: health and social gain. Health gain was concerned with increasing life expectancy and improvements in quality of life while social gain focused on improving a person's quality of life by minimising their disability and the social disadvantage associated with it. The Health Strategy articulated the government's commitment to develop local services on the basis of

the locally-assessed need. It also referred to the need for the organisation and co-ordination of services and the implementation of initiatives to increase equity and access of service for people with disabilities. This strategy was later replaced by the 'Quality and Fairness – A Health System for You,' launched in 2001, and this was the catalyst of the health reform programme.

**Figure 1: Irish legislative, governmental, health service and women's health documents**



### 3.3.3. A Plan for Women's Health

'A Plan for Women's Health' (Department of Health, 1997) was the first policy to concentrate specifically on women's health, and evolved from growing concerns that women's health needs were not being adequately addressed by the health services. The Plan was a fulfilment of the commitments made in the preceding policy document 'Shaping a Healthier Future' (Department of Health, 1994) and evolved from an 18-month consultation process. The Plan was devised against the backdrop

of the Programme of Action of the International Conference on Population and Development, and the Beijing Declaration and Platform for Action.

It was envisaged that the plan would provide a coherent framework for the improvement of women's health and health services for women. Four main objectives were presented in the plan including maximising the health and social gain of all Irish women, the creation of a women-friendly environment and increasing consultation and representation of women in the health services. The consultation process facilitated dialogue around the difficulty experienced by women with disabilities in accessing health services. It identified how maternity services did not address the particular needs of women with a disability. In response, the Department of Health set out a commitment and action plan to address the issues. The action plan included the expansion of services for people with disabilities. Each Health Board was to develop a women's health plan and were requested to conduct a review to determine to what extent services were accessible to women with disabilities. Disability training and awareness was to be provided to all staff and funding was available for innovative projects and approaches that improved services for women with disabilities. Under the health reform programme, the health boards were dissolved and their functions transferred to the Health Service Executive. However, despite these commitments, progress on improving health services for women with disabilities is slow and more recently the development of policy documents do not appear to include these women specifically.

#### **3.3.4. The National Health Promotion Strategy**

The National Health Promotion Strategy (Department of Health and Children, 2000) briefly mentions people with physical and sensory disabilities, acknowledging that the maintenance of a healthy lifestyle is equally as important for these individuals as it is for the wider population. The strategy sets out specific goals in relation to maternal health, women and disadvantaged groups. The strategy recommends that health promotion programmes be adapted to address the needs of people with physical and sensory disabilities and recommends that a process of consultation with appropriate service providers, organisations, individuals and carers be undertaken to achieve this.

Although reference to the specific needs of women with mental health difficulties during pregnancy, childbirth and the postnatal period is not mentioned in the strategy, it does draw attention to the fact that the most common cause of women being admitted to an inpatient psychiatric unit is depression. The promotion of 'positive mental health especially at vulnerable times in women's lives' is identified as one of the objectives of the strategy (Department of Health and Children, 2000:42).

As with so many other policy documents, the National Health Promotion Strategy briefly mentions both intellectual disabilities and maternity care, but not together. The strategy, whilst recognising that this group of people may have unique health promotion and education requirements, does not offer any suggestions as to what they may be. The strategy does, however, encourage consultation with individuals, carers and organisations representing them. No evidence was found in any documents to suggest that women with intellectual disabilities were receiving maternity care that was geared specifically to their needs. The absence of data relating to such women is worrying as it has been acknowledged that accurate, up-to-date information is essential for the development of effective policy and planning (Crisis Pregnancy Agency and Department of Health and Children, 2006). Furthermore, the Women's Health Council (WHC, 2007b) has called for attention to be given to uncovering data on the needs of women with intellectual disabilities in accessing maternity care so that effective policies and processes may be developed at national, regional and local levels.

### **3.3.5. Quality and Fairness – A Health System for You**

The strategy contained in 'Quality and Fairness – A Health System for You' (Department of Health and Children, 2001a) was considered the blueprint for the development of the public health services. It identified 4 national goals: fair access, responsive and appropriate care and high performance. Similar to the preceding strategy, it was underpinned by the principles of equity, people-centeredness, quality and accountability. The strategy outlined the government's intention to 'concentrate on the enhancement of the health and personal social service needs of people with disabilities' (Department of Health and Children, 2001a:141) in order that each

individual with a disability will achieve his or her full potential and maximum independence' (Department of Health and Children, 2001a:141). It recognised that people with physical and sensory disabilities experience considerable unmet needs and called for increased investment and the expansion of services for this population.

Referring to maternity services, the strategy recognised that models of maternity care were changing and that women were demanding greater choice in relation to their place of giving birth and the care they received. In the absence of any national maternity strategy, the Department of Health and Children proposed setting up a working party to examine maternity care as part of the National Health Strategy (Department of Health and Children, 2001a), with the aim of providing all women with access to a woman-centred maternity service. This should – theoretically - meet the maternity needs of women with all types of disability and develop the interprofessional knowledge base for, in particular, women with intellectual disabilities or mental health difficulties.

The strategy also emphasised the importance of primary care and the provision of services in a cohesive and continuous manner, and proposed the introduction of team based primary care services on a phased basis. The multidisciplinary team would comprise of a GP, nurses, midwives, health-care assistants, home helps, physiotherapists, social workers, occupational therapists, and administrative resources. For women with disabilities, team based primary care would facilitate accessibility and the provision of women-centred care in a co-ordinated and integrated manner.

### **3.3.6. Primary Care: a new direction**

This strategy reinforced the contention that primary care is the most appropriate setting to meet the majority of health and social service needs of the general population in Ireland (Department of Health and Children, 2001b). The strategy sets out 20 action plans, to implement the proposed model of Primary Health Care and recommends that primary healthcare centres be accessible to people with a disability. It advocates disability training and awareness for all staff and recommends that a review of the provision of primary care and social services should be

conducted. However, 7 years on from the publication of the strategy, realisation of its vision and objective is yet to be achieved for people with disabilities.

### **3.3.7. A Vision for Change**

'A Vision for Change', the report of the expert group on mental health policy, has been accepted by the government as the basis for future development of mental health services. Section 15.5.6 of the document specifically refers to perinatal psychiatry stating that ... *'One adult psychiatrist and senior nurse with perinatal experience should be appointed to act as a resource nationally in the provision of care to women with severe perinatal mental health difficulties'* (Department of Health and Children, 2006a:156). The document states that this perinatal mental health resource should be provided in a national maternity hospital. This review also recommends the development of a specialist community-based intellectual disability mental health service to meet the needs of women with intellectual disabilities who also have mental health needs. It is proposed that this be based on citizenship, inclusion and accessibility. This service may, perhaps, inform the development of a specialist maternity service for women with intellectual disabilities.

### **3.3.8. The National Women's Strategy**

Ten years after the publication of 'A Plan for Women's Health' (Department of Health, 1997), the National Women's Strategy (Department of Justice, Equality and Law Reform, 2007) was developed to address all the key areas of concern for women in Irish contemporary society, and was deemed to be a strategy that would benefit many women. The Strategy asserts that all government policies take account of the requirements of women with special needs, including women with disabilities. The document refers to the key issues highlighted by the National Disability Authority in relation to women with disabilities, noting that women encounter barriers and challenges when accessing mainstream health services and how such challenges may discourage women from seeking appropriate health care. Despite its vision, none of the strategy's 20 objectives or 200 planned actions specifically refer to women with disabilities. One action plan (objective 8) does refer to the provision of services that will facilitate full access to service and information during pregnancy, childbirth and the postnatal period (objective 8c). Objective 8a identifies the need to

improve the health status of women through gender-focussed policies, and 8c refers to ensuring that 'antenatal care, maternity services and postnatal care are woman-centred.' In addition, under objective 8d, which is focussed on improving the mental health status of women, one of the action points is to 'consider the introduction of awareness campaigns relating to mental health among women in the perinatal period.' (Department of Justice, Equality and Law Reform, 2007:76).

### **3.3.9. The National Intercultural Health Strategy (2007-2012)**

Published earlier this year, the National Intercultural Health Strategy (2007-2012) embraces 2 core objectives identified in the Transformation Programme (2007-2010). The first of these is the improvement of people's experiences of the services and their outcomes through developing, changing and integrating the services in line with best practice (HSE, 2008). The second objective is the protection, promotion and improvement of the health and well-being of the population based on identified need. The strategy was informed by a 9-month national consultation with service users and service providers. It is a supportive framework for healthcare providers and service users to work within the auspices of participation, collaboration and cooperation when designing, planning, implementing and evaluating healthcare services for people from diverse cultural and ethnic backgrounds. Few issues emerged around the area of disability (HSE, 2008:90); however, the strategy recommends the implementation of disability legislation and recognises how this framework provides an opportunity to collaborate with disability organisations to identify and address specific healthcare needs for people with disabilities from diverse cultures and ethnic backgrounds. It advocates the implementation of the principle of Universal Access, which ensures that health services are accessible to all. Health services must also be flexible and sensitive to the needs of people from diverse cultural and ethnic backgrounds.

The strategy anticipates that sexual health for persons from minority ethnic groups will be addressed within the context of the forthcoming National Sexual Health Strategy. It notes how the deliberations and work of the Expert Advisory Group for Maternity Services will identify the priorities and actions required to address the needs of women from diverse ethnic minorities and cultures (HSE, 2008). It suggests that



the ethnic identifier will facilitate the development of information regarding the maternity needs of women from diverse ethnic and cultural groups. It recommends that the coordinated development of guidelines governing the production of translated material regarding entitlements, service user rights and complaints mechanisms should be prioritised and actioned. The strategy also recommends that mental health services be provided in a culturally sensitive manner within the context of the model of community mental health endorsed in the 'Vision for Change' policy document (DoHC, 2006a) and be appropriately resourced to provide auxiliary services including the provision of interpreters.

### **3.4. Implementation of the Disability Act (2005) with the health services**

#### **3.4.1. Introduction**

In the absence of specific policies governing the provision of services for women with disabilities during pregnancy, childbirth and early motherhood, the Health Service Executive, as a public body, is obliged to fulfil the requirements set out in Part 3 of the Disability Act (2005) and this obligation extends to all health and social services 'provided by or on behalf of the Health Service Executive' (Government of Ireland, 2005a:10).

#### **3.4.2. Assessment of needs**

Part 2 of the Act refers to the delivery of individual health, education and personal social services for people with disabilities. The impartial independent assessment of needs required by Sections 8-10, which is currently restricted to 0-5 year olds, will be undertaken by an assessment officer 'regardless of cost or capacity' (Government of Ireland, 2005a:11) and the aim is to identify the appropriate health services that will ameliorate the person's disability. The Health Information and Quality Authority (HIQA) have developed a set of standards to regulate the assessment process, which were adopted by the Department of Health in 2007 (HIQA, 2007).

The Act prescribes that adequate information relating to the assessment process and the outcome of such assessment should be provided to all applicants. Effective

communication should be facilitated and should promote dialogue with the applicant, and cognisance must be taken of the person's opinions and views regarding their needs or preference in relation to the provision of health services. Provision for a relative, guardian or personal advocate to apply for an assessment on behalf of the person with a disability is also provided for in the Act. In certain circumstances, employees of the Health Service Executive may initiate an assessment of need on behalf of the person. Once the assessment of needs is completed a report is sent to the Health Service Executive. This report will include a determination of the appropriate services for the person and thereafter a service statement will be developed by a liaison officer. The person will then be furnished with an assessment report outlining the services that are to be provided for them by the Health Service Executive. The assessment report will provide information on -

- whether or not the person has a disability as defined under the Disability Act,
- the nature and extent of the disability;
- the individual health needs that arise as a result of their disability;
- a statement of the appropriate services needed to alleviate and ameliorate the disability and to address the person's individual needs;
- the timescale for the delivery of the services and
- when a review of the assessment should occur.

Service statements can be amended when necessary, reflecting a change in circumstances of the person or of any elements of the service statement. The applicant will meet with the liaison officer to review the provisions of the services indicated in the service statement. A means of redress is also established under Part 2 of the Act. If the person is not satisfied with the outcome of the assessment, the individual is afforded the right to pursue a complaint through an independent redress mechanism. While maternity services are not covered under part 2 of the Disability Act, there are protocols for referral to appropriate services and agencies set out in the Standards for the Assessment of Need issued by the Health Information and Quality Authority.

### **3.4.3. Accessibility of public buildings**

Under Part 3 of the Disability Act (Government of Ireland, 2005a) the Health Service Executive is required, as and from the 31<sup>st</sup> of December 2005, to integrate, where appropriate and practical, their services for people with disabilities. Assistance to services must be made available to people on request. Access officers should be appointed in the HSE 'to provide or arrange for and co-ordinate the provision of assistance and guidance to people with disabilities accessing its services' (Government of Ireland, 2005a:27). Furthermore the Health Service Executive, when appropriate, are obliged to consult with persons with appropriate expertise and skills either internal or external to the organisation to provide advice on how their services can be made accessible to persons with disabilities. The National Disability Authority has devised a statutory Code of Practice (NDA, 2006) to assist public bodies such as the Health Service Executive to comply with Part 3 of the Act.

### **3.4.4. Appropriate and accessible communication**

Under the Act, the Health Service Executive has a statutory obligation to ensure that it procures, wherever practicable, goods and services that are accessible to people with disabilities. The HSE is also obliged to ensure that its information and communication with any persons with a hearing or visual impairment, or with an intellectual disability is, as far as is practicable, accessible and easily understood. Electronic information must, as far as is practicable, be compatible with adaptive technology.

### **3.4.5. Sectoral plans for improvement of access to health services for people with disabilities**

Section 31-37 of the Disability Act (2005a) refers to the preparation and revisions of sectoral plans. The plans ensure that access to services for people with disabilities will continue to be an integral part of service planning and provision. Six key departments, one being the Department of Health and Children, are obliged to submit sectoral plans to the Department of Justice, Equality and Law Reform outlining the Department's actions to meet its obligations as set out in the Act. To monitor the progress of implementation of the sectoral plan, progress reports must be completed and published at intervals of 3 years. Acknowledging the complex and evolving process involved in meeting the requirements of the plan, the Department of Health

and Children and the Health Service Executive have committed to publishing an annual review of progress for the first 3 years of the disability strategy. The first progress review identified that significant progress was made in the first year of implementation of the plan (Department of Health and Children, 2007a). The Department of Health and Children and the Health Service Executive identified some of the measures taken 'to integrate where practical and appropriate, services for people with disabilities' (Government of Ireland, 2005a:13). Assistance to access will be available to persons on request. Four access officers have been appointed and their function is to provide, arrange and co-ordinate the provision of assistance and guidance to people with disabilities accessing services in the Department. An inquiry officer has also been appointed with the remit of investigating and reporting on complaints received. Similar appointments have been made in the Health Service Executive. An internal implementation overseeing group was established and its remit is to monitor compliance with Part 3 of the Disability Act. It is envisaged that this group would act as a resource and provide advice and support in relation to the specific provision indicated in Part 3 of the Act.

Future appointments include a national specialist in accessibility. Recently the Health Service Executive conducted an audit of 40 health centres in the Dublin Mid-Leinster region. The audit was to determine the level of accessibility and to identify aspects of the design, layout and use of the building that adversely affect people with disabilities. At present the Health Service Executive are reviewing the results and an audit tool, which will be used nationally to evaluate the accessibility of existing health services, is currently being developed. The expected completion date of this national audit is the end of 2008. In addition to the audit, the Health Service Executive are developing a number of guidelines and protocols to ensure that all communications with its various agencies are in an accessible and appropriate format. The Health Service Executive's National Communications Unit have requested all services to initiate a review of their communication mechanisms to ensure that information is provided in an appropriate and accessible format for all persons availing of their services.

Accessible public transport extends beyond physical and infrastructural access; it refers to the person's ability to gain information about the service(s) available and the ability of service(s) to address the person's needs. In accordance with the requirements of the Disability Act 2005 (Government of Ireland, 2005a), the Department of Transport published its first sectoral plan '*Transport Access for All*' in July 2006 (Department of Transport, 2006). The Plan sets out the government's objectives and targets to ensure that all modes of transport in Ireland are accessible for all of its citizens. Two years after its implementation, the first review of the plan was undertaken. A range of stakeholders including disability organisations and transport providers were consulted and subsequently a revised sectoral plan was published (Department of Transport, 2009).

The review indicated that some progress towards an accessible public transport system in Ireland was achieved, and that preparatory work on accessible passenger information systems is underway. It is envisaged that these systems will enhance the travel experiences for people with mobility, sensory and cognitive impairments (Department of Transport, 2009). For users of municipal bus services, 74% of the Bus Átha Cliath buses fleet are low-floor wheelchair accessible. While all (100%) of the Bus Éireann city fleet in Cork, Limerick, Galway and Waterford are low-floor wheelchair accessible. In addition Bus Éireann has also purchased a number of wheelchair accessible coaches. For rail passengers, Iarnród Éireann are replacing its remaining inaccessible InterCity trains with accessible trains and the aim is to have all scheduled inter-urban passenger rail services accessible by the end of 2009. With regard to taxis and hackneys, the Commission for Taxi Regulation devised and introduced new standards to address the accessibility of vehicles used for such services. This body, in consultation with the Department of Transport, is also developing proposals to address the economic and practical challenges of increasing the proportion of wheelchair accessible taxis nationally. Ireland has also enforced the 2006 EU Regulation relating to the rights of disabled persons and persons with reduced mobility when travelling by air (European Union and Council of Europe, 2009) and an independent public body, the Commission for Aviation Regulation was established to enforce and monitor this legislation. Currently the Department of

Transport is engaging with the EU Commission and other EU member states to introduce similar requirements for maritime passenger transport.

While acknowledging the restraints of the current economic climate, the revised plan (Department of Transport, 2009) reinforces the concept of '*Transport Access for All*' and subscribes to the lifecycle approach advocated in Towards 2016 (Government of Ireland, 2006). It demonstrates the government's commitment to the continual delivery of an accessible, integrated public transport service for people with mobility, sensory and cognitive impairments by 2015. It promotes consultation and collaboration with other agencies e.g. the Centre for Excellence in Universal Design, the Public Transport Accessibility Committee, disability user groups and other relevant Government Departments e.g. the Department of the Environment, Heritage and Local Government in order to achieve the stated objectives and targets.

Supplementing the provisions of the sectoral plan are 2 key policies, the National Development Plan (NDP) (2007-2013) and Transport 21 (Government of Ireland, 2005b). The NDP reiterates a commitment to accessible public transport and provides funding for the retrofitting of vehicles, facilities and services to meet this objective. Transport 21 (Government of Ireland, 2007d), the 10-year capital investment programme for transport in Ireland, promotes accessibility of transport in 2 ways. First for any new infrastructural projects accessibility will be a consideration from the design stage. Secondly, funding will be available for the phased modification of existing infrastructure to render it accessible. The provisions of the plan apply to all operators of public transport services, both public and private.

Detailed progress reports, outlining the progress in achieving the objectives and aims of the plan will be prepared and submitted periodically for consideration by the National Disability Strategy Stakeholders Monitoring Group. The process will be transparent; reports will be available to all interested parties and, from 2009, will be published on the Department of Transport's website once they have been considered by the National Disability Strategy Stakeholders Monitoring Group. The next review of '*Transport Access for All*' will be in 2011 and every 3 years thereafter (Department of Transport, 2009).

### **3.5. Guidelines for Health Professionals**

Recently the Health Service Executive and the Crisis Pregnancy Agency (CPA) published a set of guidelines for health professionals providing care to women with a concealed pregnancy (HSE and CPA, 2009). The guidelines outline the various reasons why a woman may conceal a pregnancy and suggest that, for a woman with a disability, concealing her pregnancy is a mechanism that may help deflect the attitudes of others who do not support her decision to become a parent. Furthermore for women with a mental health illness or intellectual disability, their illness or impairment may impact on their capacity to identify and cope with the pregnancy (HSE and CPA, 2009). The guidelines are aimed at multidisciplinary professionals working in a hospital based maternity setting. They propose the implementation of 8 guiding principles to reassure the woman when disclosing her pregnancy and to encourage her to engage with the maternity and other supportive services available to her. The guidelines recommend that a letter of intent be drafted by the woman and the Social Worker in the antenatal period. This letter should include the woman's demographic details, a statement regarding her wishes to assume the status of a 'confidential patient', her expectation and wishes of the antenatal, intranatal and postnatal period, her wishes with regard to her next of kin and any directions in relation to the notification of Public Health Nurse, General Practitioner and the HSE Notification of Births Office. Once drafted the letter should reside in the woman's chart and be updated at regular intervals. If a woman presents in labour the midwifery staff are encouraged to draft the letter of intent with the woman. The guidelines recognise the different roles of various professionals involved in the provision of care for a woman with a concealed pregnancy and provide guidance to each profession caring for a woman during pregnancy, childbirth and the postnatal period. At the time of writing NDA is currently working in partnership with the Crisis Pregnancy Agency to review international good practice in the provision of information and supports to people with intellectual disabilities who experience a crisis pregnancy.

### 3.6. Summary

This chapter identified and discussed the policies that govern procedure and practice in service provision at Health Service Executive level in Ireland. The HSE was established in 2005 following the Health Act 2004 (Government of Ireland, 2004e), and is responsible for the provision of health and personal social services in Ireland. Its transformation programme 2007-2010 (HSE, 2006), which establishes the organisation's mission and purpose, proposes the transformation of maternity services as one of its major actions.

The Health Service Executive has no specific policies documented that cater for women with disabilities during pregnancy, childbirth and early motherhood. However, they are obliged to fulfil their statutory requirements mandated in the provisions of the Disability Act (Government of Ireland, 2005a), which forms the core element of the Disability Strategy (Department of Health and Children, 2006b). The Disability Strategy is a designated policy framework that confers a duty of care on all public bodies to ensure that services provided by the organisation are accessible, appropriate and equitable for people with a disability.

Eight national policies were reviewed and, although none related specifically to women with disabilities who wished to access maternity services, some recommendations contained within them were applicable. For example, recommendations from 'A Vision for Change' (DoHC, 2006a) include the appointment of an adult psychiatrist and senior nurse with perinatal experience to care for women with severe perinatal mental health difficulties. This review also recommends the development of a specialist community-based intellectual disability mental health service. Similarly, the National Health Promotion Strategy (DoHC, 2000) recommends that health promotion programmes be adapted to address the needs of people with physical and sensory disabilities, but no specific detail is given in the area of women or maternity care.

It is anticipated that some of the legislation recently enacted will provide for better care and facilities for women with disabilities in the future. For example, the Disability



Act (Government of Ireland, 2005a) requires that public bodies such as the Health Service Executive are required to ensure that their public buildings are accessible to people with disabilities by the year 2015. Under the terms of the Disability Act, sectoral plans to implement the requirements were published in 2006 by 6 government departments, one of which was the Department of Health and Children. These plans are subject to annual review, which should lead to improved facilities being made available to all persons with disabilities. However, the absence of any specific national policy relating to the care of women with disabilities wishing to access services during pregnancy, childbirth and early motherhood is of concern. Recent guidelines for health professionals providing care to women with a concealed pregnancy, produced by the HSE and the CPA, are an important new development and more such guidelines should be encouraged. The following chapter sought to ascertain any policies provided by professional bodies in Ireland in the area of service provision during pregnancy, childbirth and early motherhood.

## **Chapter Four: Current policies governing procedure and practice in service provision at relevant professional body level**

### **4.1. Introduction**

This section identifies and discusses the current policies that govern procedure and practice in service provision at relevant professional body level. Two professional regulatory bodies were contacted in the course of the review (An Bord Altranais (the Irish Nursing Board) and the Medical Council) and 2 bodies responsible for further medical education (the Irish College of General Practitioners and the Royal College of Physicians of Ireland).

An Bord Altranais and the Medical Council are the statutory bodies responsible for the mandatory registration and professional conduct of qualified nurses and midwives, and doctors, respectively, and for regulation of the practice of their appropriate professions. Both institutions are also responsible for ensuring the quality of education and training, disciplinary procedures, and the protection of the public.

The Irish College of General Practitioners is recognised by the Medical Council as the representative organisation responsible for education, training and standards in general practice, which is a post-graduate medical discipline. The Royal College of Physicians of Ireland similarly conducts, and sets the standards of, postgraduate medical education and training of physicians in 25 or more different specialties. It is composed of 6 training bodies, including the Faculty of Paediatrics and the Institute of Obstetrics and Gynaecology.

All 4 bodies regulate the education and training of their respective profession or discipline and are not directly involved in the development of policies relating to service provision. However, each body provides professional guidance and support including guidance on the etiquette, ethical conduct and behaviour that each professional must adhere to when engaging and interacting with the public.

## 4.2. An Bord Altranais

Three core documents published by An Bord Altranais were reviewed and An Bord Altranais were contacted to locate any further policies. The documents reviewed were:

- The Code of Professional Conduct for each Nurse and Midwife (An Bord Altranais, 2000b);
- Scope of Nursing and Midwifery Practice Framework (An Bord Altranais, 2000a);
- Guidelines for Midwives 2001 (An Bord Altranais, 2001).

Although the documents identify the expected standards of professional conduct, scope of practice, and roles and responsibilities of midwives, none make any reference to the care of women with disabilities.

## 4.3. The Medical Council

The Medical Council's guide to ethical conduct and behaviour refers to people with disabilities. Section B of the guide clearly identifies how such persons are entitled to the same treatment and respect for autonomy as non-disabled people (The Medical Council, 2004), but no further details are given. No reference is made to women with disabilities or their care.

## 4.4. The Irish College of General Practitioners and the Royal College of Physicians of Ireland

Similarly, the Irish College of General Practitioners and the Royal College of Physicians of Ireland were contacted but no relevant policies were identified. Both reinforced their role in the regulation of education, training and professional conduct of their respective professions.

## 4.5. Summary

Despite perusal of all available documents, and contact with all 4 professional or academic bodies, very little was found in relation to policies that govern procedure

and practice in service provision. In particular, there were no policies explicitly referring to the care of women with disabilities when accessing services during pregnancy, childbirth and early motherhood.

## **Chapter Five: Current policies governing procedure and practice in service provision at maternity hospital/unit level**

### **5.1. Introduction**

Part of the requirement of this review was to identify, access and discuss current policy governing procedure and practice in service provision at maternity hospital/unit level for women with disabilities when accessing publicly-funded Irish health services during pregnancy, childbirth and early motherhood. To determine the existence of and to gain access to such policies, all 19 publicly-funded maternity units in the Republic of Ireland were invited to participate in a telephone survey. All 19 units consented to do so and this chapter presents the findings from the survey.

### **5.2. Aim of survey**

To identify, access, review and discuss the policies that govern practice and procedure in service provision for women with disabilities who need to access publicly-funded Irish health services during pregnancy, childbirth and early motherhood.

### **5.3. Development of the survey instrument**

#### **5.3.1. Initial design**

A web based search was conducted to identify a tool that could be used to fulfil the aim of this survey. No suitable tool was located so a customised questionnaire was developed. National and international legislation and existing policy documents, where available, informed the design and content of the tool. Initially, the tool was composed of 64 open and closed questions. The open questions afforded the respondents the opportunity to elaborate on services provided to women with disabilities within their institution. The tool sought to gather information on accessibility including access to the built environment, effective communication and provision of information. Information was sought on the perinatal mental health

screening procedures adopted by each institution, the availability of specialist mental health services, ongoing professional development and the level of support available to women with disabilities.

### **5.3.2. Testing of questionnaire**

Face and content validity was determined by members of the project's Steering Group, experts working within the non-voluntary and voluntary disability organisations and women with a physical disability, sensory impairment or mental health illness. Subsequent comments, amendments and suggestions from the various groups and experts were incorporated and the final tool consisted of 72 open and closed questions (Appendix 3).

## **5.4. Accessing the population**

An information letter explaining the purpose of the survey, and accompanied by a copy of the initial questionnaire, was sent to all Directors of Midwifery/Nursing in all 19 publicly-funded maternity units in the Republic of Ireland. The letter requested that the Director nominate the most appropriate person to answer the questions on the survey, during a telephone interview. Directors from all 19 maternity units (Appendix 4) consented to participate and nominated a person to complete the survey. A member of the study team then contacted the nominated person to arrange a suitable date and time to complete the survey. The nominated persons were representative of both the managerial and clinical domains of midwifery and included Directors of Midwifery and Nursing, Assistant Directors of Midwifery and Nursing, Clinical Midwife Managers, Health Promotion Officers, and Practice Development Co-ordinators.

## **5.5. Data collection**

All telephone interviews took place in the period 20<sup>th</sup> August to 3<sup>rd</sup> October 2008. The survey was completed at a convenient time for the respondent and the researcher. Generally it took 15–40 minutes to complete, with the duration dependent on the

respondents' responses. Anonymity was maintained by allocating a code number to each unit and all data were kept confidentially.

## 5.6. Results

### 5.6.1. Existence of policies relating to the provision of services for women with disabilities

Only one (5%) of the 19 maternity units has developed a written policy on the provision of services for women with disabilities. The unit is a large maternity hospital, with 7,000-8,000 births per year. A copy of the policy, which was devised by the local guideline group and is implemented in the parent education department, was received and reviewed. The focus is education and exercise in pregnancy and parenthood. It is a relatively new policy and has not undergone a review process as yet but there is a plan to review it every 2 years. The policy appears to have been developed before the legal requirements for accessible public services enacted by the Disability Act 2005, and set out in the Code of Practice on Accessible Public services 2006, came into force and does not appear to have been modified to reflect any changes these might require.

The policy aims to develop parent education packages for specialised groups including women with a physical, sensory or intellectual disability. It highlights the importance of a fully accessible environment, the need to integrate women into mainstream classes but to be flexible and adaptable in order to meet individual needs. It recognises the need to orientate women to the hospital and birthing environment and to link them with organisations with specialist knowledge of disability and parenting. The policy notes how women with a hearing impairment are likely to be accompanied by a sign language interpreter but if they are not, the antenatal educator must be aware of the barriers that impede the women's ability to lip read. No reference is made to the education department or hospital engaging the services of a sign language interpreter.

Section 28 of the Disability Act 2005 requires a public body, on request, to communicate the contents of any communication in a form which is accessible to the person concerned. The hospital policy recommends using text messaging or fax as effective methods of communicating with deaf women but it does not detail other possible means of communication e.g. use of e-mail, large print or Braille to communicate with women with vision impairments, or use of loop systems, speedtext or booking sign language interpretation services for women with impaired hearing.

It states that all information should be provided in a clear and concise format, and that antenatal educators, when facilitating classes for vision impaired women, should source and use tactile teaching aids or devices. For women with an intellectual disability, the policy advocates that teaching goals should be specific to this cohort and the content of the class should be based on their identified needs. It further prescribes that the educator must ensure that the woman/couple have access to support groups or parenting groups in their locality. Written information should be in easy to read format, well designed and colourful. During the telephone interview, the respondent at this hospital indicated that the policy is partially implemented by clinical staff but was unable to comment on whether or not the policy was known to all clinical staff. The policy is not accessible on the hospital website, nor available in alternative formats such as Braille or audio format.

#### **5.6.2. Existence of written guidelines for staff assisting women with disabilities**

In addition to having no written policies, 18 maternity units do not have written guidelines readily available to frontline staff involved in assisting women with a disability. However, respondents indicated that the midwives would have an awareness of the clinical guidelines developed and published by organisations such as the National Institute for Health and Clinical Excellence (formerly 'NICE'). In one maternity unit, direction on engaging the services of a sign language interpreter is provided to the administrative personnel located in the antenatal clinics. Two of the maternity units acknowledged the importance of clinical guidelines but neither have any plans to develop them in the foreseeable future.



### **5.6.3. Assessment of needs of women with disabilities**

Seventeen of the 19 units (90%) indicated that they conduct an assessment of needs for women with disabilities. The survey results indicated that women with a physical disability or an enduring mental health illness are marginally more inclined to have an assessment of need conducted than a woman with a sensory or intellectual disability (Appendix 5).

The assessment of needs tends to be conducted by a number of health professionals with midwives identified by 16 of the 17 units (94%) as the most likely person to conduct the assessment. In 11 units, consultant obstetricians conduct an assessment of needs while physiotherapists, social workers, occupational therapists, general practitioners, psychiatrist, speech and language therapists, liaison mental health nurses and/or parentcraft education midwives are other professionals described as likely to be involved in the assessment process.

In addition to a formal assessment of needs, 17 maternity units (90%) have procedures in place for women with a disability to make their needs known to clinical staff. These procedures include an open discussion between the women and the midwife carried out on a one to one basis, generally at the initial booking interview/visit around 12 weeks' gestation. The woman's needs are determined and an individualised care plan is devised and implemented to respond to and address her needs. If warranted, the woman is referred to appropriate support teams or specialists, and services and/or support mechanisms are instigated.

### **5.6.4. Accessibility of services**

Accessibility is an essential concept and encompasses access to facilities, effective and appropriate methods of communication and information. To date, only 2 maternity units (11%) have appointed an access officer, disability officer or special needs officer (Appendix 5). Eleven units (58%) do not have a designated person that clinical staff can contact in the event of any queries or issues regarding services for women with a disability. An access audit has been conducted in 6 (32%) of the units surveyed. Respondents were asked to identify any areas that were deemed to be inaccessible or any infrastructural barriers highlighted during the audit process.

These included insufficient disability parking, doors not wide enough to permit a wheelchair to access; inaccessible bathroom and toilet facilities (2 units); inconsistent floor level; inconsistent door knobs/handles and the presence of steps or ramps that impede access for women using a wheelchair, or for those with a vision impairment.

A formal review of the accessibility of the services provided was carried out in 6 (32%) of the units. In 5 of these units, internal experts were used and in the sixth, both internal and external experts were involved. These experts were from national and international organisations and agencies and included a UK Professor, a disability awareness group, persons associated with the ISO certification and groups assessing the organisation's conformability with legislation such as the Equal Status Act (Government of Ireland, 2000) and HSE guidelines on an accessible built environment.

#### **5.6.5. Issues regarding care of women with a physical disability**

The survey revealed that in the 13 units who have not conducted a formal review of the accessibility of their services, 12 of them indicated that in their opinion all departments/areas are accessible to women with a physical disability (Appendix 5). One unit identified that the Special Care Baby Unit (SBCU) and bathroom facilities are inaccessible to these women mainly because of infrastructural barriers such as the doors being very heavy or too narrow. However, assistance is available at all times to women who use a wheelchair in all 19 maternity units. Written information on the accessibility of relevant areas/wards is provided to women with a physical disability by 6 (32%) of the units. Seventeen units (90%) have height adjustable beds suitable for women with a physical disability and one of the 2 units which do not, are presently engaging in a phased introduction of height adjustable beds to all departments, but this initiative is hindered by resource issues. Twelve (63%) of the units have special equipment such as a hoist available on the labour ward/delivery suite. Two of the labour wards/delivery suites (11%) are located in relatively new buildings that conform to the accessible building regulations and requirements.

#### **5.6.6. Issues regarding care of women with a sensory disability**

Four of the units (21%) conducted a review specifically to ascertain the accessibility of the hospital environment for women with a vision impairment (Appendix 5). For women with a vision impairment, guide dogs facilitate navigation around the physical environment, and the majority of maternity units do permit guide dogs in the hospital. For one unit, the issue has not yet arisen. The majority of units who permit guide dogs do have restrictions on where the guide dog may or may not go. In one unit (5%), guide dogs are only permitted following consultation with the Director of Midwifery and Nursing and the Infection Control Officer. Infection control issues were cited as the main reason for applying restrictions on where a guide dog may be permitted to go. Generally guide dogs are not permitted in areas such as the operating theatre, labour ward/delivery suite; neonatal unit; special care baby unit (SCBU) and diagnostic areas e.g. ultrasound department. Two units (11%) do not permit guide dogs in the antenatal or postnatal wards/suites.

Staff in one of the 19 units (5%), receive training in sighted techniques and methods to familiarise women with a vision impairment to the layout of the ward and immediate environment. Seventeen units (90%) indicated that prior to any hands-on contact, all staff introduce themselves to women with a vision impairment. Assistance for vision impaired women is available 'all of the time' in 12 units (63%) and is available in the remaining 7 units (37%) if pre-arranged. Nine of the units reported having specific provisions to support women who are vision impaired. Information is available in Braille format in 3 units, while 2 units have information in large print or audio format. However, only 4 units (21%) had been assessed in terms of accessibility for people with a vision impairment.

Similarly, 12 of the units (63%) indicated that provisions are in place to support women with a hearing impairment, when they access the services. All of these units have access to, and will engage the services of, a sign language interpreter, information is available in plain English format and alternative modes of communication including text, fax or email, can be employed if the woman requests them. Two units (11%) have a loop system installed. None of the units reported using a minicom. Four units use text messaging as a method to notify women about clinic

appointment(s). Assistance for hearing impaired women is available 'all of the time' in 9 units (47%) and is available in 7 units (37%) if pre arranged, but in the remaining 3 units (16%) assistance is not available.

#### **5.6.7. Issues regarding care of women with mental health difficulties**

The survey revealed that 17 maternity units (90%) do screen all women attending the maternity services, for mental health illness (Appendix 5). Depression, postnatal depression, anxiety and psychosis are the more prevalent conditions screened for, while screening for bipolar disorder, and risk factors associated with mental illness such as domestic violence and sexual abuse occurs to a lesser extent, with one unit also screening for genital mutilation. All units except one provide specific training and education for staff in mental health conditions, domestic violence, sexual abuse and disability. Training and education on postnatal depression is the most common, followed by domestic violence (Appendix 5).

The majority of units (n=12, 63%) do routinely provide verbal information on perinatal mental health issues to all women during the antenatal period and the information is primarily on postnatal depression. Four units (21%) provide information selectively to women who present with a history of mental health issues. In addition to verbal information, 4 units (21%) supplement with written information either in the form of the HSE mental health booklet or locally devised booklets or leaflets. In one unit the postnatal support group, together with the HSE, devised and published a leaflet that all women attending the maternity services receive routinely. Nine units (47%) screen for antenatal and postnatal depression. Three out of the 9 units use a tool to screen for antenatal or postnatal depression; 2 units use the Edinburgh Postnatal Depression Scale (EPDS) or a modified version of the Edinburgh Postnatal Depression Scale, while one unit uses a specific questionnaire developed by the perinatal team. In the other 3 units, midwives pose a specific question at the initial antenatal booking interview/visit which, with clinical observation and assessment, are the primary mechanisms employed to detect and diagnose depression in the antenatal and postnatal period.

Eleven units (58%) can access and refer women to a specialist multidisciplinary perinatal mental health service within the hospital. The team is primarily composed of a psychiatrist, clinical psychologist, specialist mental health nurse, social worker, counsellor and community health nurse. For the remaining units, external specialist services are available; however, one unit has no access to either internal or external specialist multidisciplinary perinatal services. Healthcare providers, working in the units with no access to internal specialist multidisciplinary perinatal mental health services, routinely contact general practitioners when planning the care and discharge follow-up for women with a mental health illness. Other professionals, including the public health nurse, counsellor, psychologist, psychiatrist, mental health nurse and social worker may also be contacted. Seven units (37%) report having advocacy services, either internal (4 units) or external (3 units), for women with mental health issues.

#### **5.6.8. Issues regarding care of women with intellectual disabilities**

Eight units (42%) indicated that provisions are in place to support women with an intellectual disability, when they access the services, but the remaining 11 units (58%) have none (Appendix 5). Where provisions are in place, the most likely format is a support person responsible for co-ordinating the woman's care while accessing the services. In some of the units, the woman may also choose to have a support person accompany them at all times or may have a support person on call. Advocacy services, either internal or external for women with an intellectual disability are available in 4 units. The majority of units (n=16, 84%) do not have information in appropriate formats, or tailored for use by women with an intellectual disability. In the 3 units that have information in appropriate formats (16%), the leaflets and booklets are either purchased from the Health Promotion Unit Department, Department of Health and Children or devised by midwives and antenatal educators working within the unit.

#### **5.6.9. Disability awareness and training**

The survey revealed that 4 units provide disability awareness and training for clinical staff and 5 units provide such training for non-clinical staff, primarily maternity care assistants (Appendix 5). Five units provide training and education on sensory

disability and 4 of these provide training and education on physical and intellectual disabilities also. Equality and diversity training and cultural awareness were other areas identified as areas of ongoing professional training and education.

#### **5.6.10. Liaison with community services**

In general, the majority of units have a mechanism in place for liaising with community services (Appendix 5). Eighteen units (95%) have a mechanism for liaising with community services for women with a physical or sensory disability, while all 19 units have a mechanism for women with mental health illness. Sixteen units (84%) have a liaison mechanism in place for women with an intellectual disability. The majority (n=16, 84%) of units have access to interpreters in different languages; 6 of these can access the services of sign language interpreters in non-English languages while 2 units have access to Braille translators in different languages. Three units (16%) have no access to any of these services.

#### **5.6.11. Antenatal education**

The respondents were requested to provide information on how the antenatal education department in their unit addresses the needs of women with a physical, sensory or intellectual disability, or mental health illness. Not every unit had a designated antenatal education department. All of the units that provide antenatal classes (n=18) indicated that the antenatal education departments are located in areas that are accessible to women with a physical disability. Generally, all the units would offer women the opportunity to attend mainstream sessions, all would meet with the woman to ascertain and discuss her unique and specific needs and every unit would facilitate one to one sessions if preferable.

For women with a sensory impairment, antenatal educators employ multiple methods and strategies to address their particular needs. Sixteen units (84%) have information available in audio format, which tends to be used when a woman with a vision impairment attends the classes but information in other formats, for example Braille, is not readily available. Three units (16%) provide information in pictorial format which is useful for woman with a hearing impairment. Fifteen units (79%) indicated

that they would engage the services of a sign language interpreter if a woman with a hearing impairment attended for antenatal education classes, while 4 units (21%) would encourage family members and/or friends to accompany women to the classes. Staff in one maternity unit have received sign language training. For women with a mental health illness, 10 of the units (53%) identified how the antenatal education educators would liaise, consult and collaborate with the midwife mental health specialist and/or the perinatal mental health specialist team to ensure the particular educational needs of this cohort.

#### **5.6.12. Feedback on care**

When asked if women with a disability are afforded the opportunity to provide feedback on the care they received. Sixteen units (84%) indicated that they have provisions in place to facilitate feedback. Three (16%) currently have no such provisions in place. Feedback can be provided in either verbal or written formats and a variety of tools are in use, including patient satisfaction surveys and patient satisfaction cards. Two units (11%) offer women the opportunity to attend a postnatal reunion class/session which usually occurs at 6 weeks post delivery and at this session/class midwives invite women to discuss the care they received. One unit has established a consumer group, which is another avenue to provide feedback, while another unit is in the process of establishing a similar group. Three units (16%) have a designated person (communication officer, patient liaison officer or complaints officer) to address any issues that may arise from the feedback and/or complaints mechanism. These provisions are available to all women accessing the services and generally there are no specific provisions in place for women with a disability.

#### **5.6.13. Barriers preventing units from improving services for women with a disability**

Respondents were asked to identify any barriers that impede or prevent them from improving services for women with a disability. Some units indicated that the percentage of women with a disability using their services was very small. A lack of disability awareness, training and education, the infrastructure, inappropriate funding and insufficient human resources were the most commonly cited barriers. Some

indicated that the recent HSE embargo on recruitment impacted significantly on the provision of care for all women, not just this cohort, and how in the current economic climate resourcing this area may not be considered a priority. Many of the services are administered from older buildings, so the physical infrastructure and fabric of the building impacted on women's ability to access services. Not having a designated person with expertise in the area of disabilities was cited as a barrier by 3 units. Sourcing sufficient funding to procure appropriate equipment and information was a common challenge encountered by many units.

#### **5.6.14. Supports needed to improve services for women with a disability**

When asked what supports are needed to improve services for women with a disability, many respondents identified the need for disability awareness, training and education provided regularly to all clinical and non clinical staff. One unit suggested that health professionals should undertake sign language training. Respondents called for sufficient funding to be made available to procure additional equipment e.g. auxiliary aids, hoists and/or to develop leaflets and information booklets appropriate for women with a disability. The respondents indicated the need to develop policies to guide the practice and procedures in service provision for women with a disability and one unit would like national guidelines and information from agencies such as the National Disability Authority. Three units suggest collaborating with disability organisations and developing stronger links with community services. Having a link person with expertise in the area of disability, working between the hospital and community, was suggested as potentially beneficial. This person would have a supportive role for both women with disabilities and health professionals and does not necessarily have to have a midwifery background. One unit suggested that having a specialist mental health nurse would be an advantage. In some units, renovations and improvements to older buildings are necessary if access to services is to be improved.

Over half of the units are in the process of developing or planning to develop better services for women with disabilities. These plans include structural renovations, the procurement of specific equipment and information, the establishment of a diversity



committee and developing policies pertaining to women with disabilities. One unit indicated that they would like to develop community services.

#### **5.6.15. Additional comments**

When concluding the survey, respondents were given the opportunity to provide any additional comments on the issue of services for women with a disability. Generally, the respondents indicated that the needs of this population are great and need to be addressed, especially in light of existing equality and disability legislation.

Respondents expressed a desire to improve services for women with disabilities. Many noted how services tend to be reactive and only address the woman's short term needs, with one unit finding it difficult to access specialist mental health services. Many indicated that completing the telephone survey increased awareness of the need to develop services for women with disabilities and were delighted to participate in the survey as they feel this will highlight the issues for women with disabilities on a national level and will help improve services. Respondents acknowledged the need to have accessible services for these women, and some indicated that they do their utmost to respond to women's needs on an individual basis, but this is constrained by a lack of resources and the lack of continuity of care, national standards and guidelines. Many look forward to the recommendations of the NDA/TCD study.

### **5.7. Conclusion**

The survey showed that only one out of the 19 publicly-funded maternity units has a formal written policy governing practice and procedure in service provisions for women with disabilities when accessing their services during pregnancy, childbirth and early motherhood, and this policy is mainly focused on antenatal education. However, the majority of maternity units do conduct an assessment of needs to ascertain the women's specific and individual needs. Thereafter, an individual care plan is devised and appropriate services or support mechanisms are implemented. A clear finding emerging from this study is that services tend to be more reactive than proactive and the provision of services is curtailed by many barriers including financial, infrastructural and human resources.

## 5.8. Recommendations

From the results of this survey, it is recommended that:

- Disability awareness and training should be provided for all clinical and non clinical staff;
- National policies, guidelines and standards of care that can be adopted by all maternity units should be developed and published. (An example of such a guideline is outlined in Appendix 6);
- In the absence of national policies, guidelines and standards all maternity units should develop their own policies for the care of women with a physical, sensory or intellectual disability or mental health illness;
- All maternity units should collaborate and consult with voluntary and non-voluntary disability organisations to develop and publish standardised and uniform information booklets suitable for women with a physical, sensory or intellectual disability or mental health illness;
- The physical infrastructure and equipment of all maternity units should be reviewed and upgraded to provide accessible and suitable services for women with a physical, sensory or intellectual disability or mental health illness; Maternity units should have procedures in place to organise appropriate means of communication with women with disabilities who so require it;
- All maternity units should review their policies on the acceptance of guide dogs in main hospital areas.

## **Chapter Six: A comparison of Irish disability policy with international standards**

### **6.1. Introduction**

Ireland is not alone in having very limited guidance for women with a disability accessing the publicly-funded health services during pregnancy, childbirth and early motherhood at national health service level, professional body and local maternity hospital/unit level; this is comparable to the international situation. The legislation and relevant policy documents of 9 countries were reviewed: the United Kingdom (UK), the Netherlands, Sweden, Norway, Denmark, New Zealand (NZ), Australia, Canada and the United States of America (USA). The UK and the last 4 countries were chosen as they are English-speaking countries, and the remaining 4 provided a selection of European Union member states regarded as leaders in social services.

The policies of each country reviewed are discussed individually, with those relating to people with different disabilities presented separately as necessary. Any legislation relating to the care of people with disabilities is outlined first, followed by a discussion of guideline documents from the relevant Department of Health, national institutes and professional bodies. Any recent policy documents are then presented. No country had one clear policy or guideline applicable to the care of women with disabilities when accessing maternity services in pregnancy, childbirth and early motherhood. An example of a 'best practice' guideline was developed from a compilation of the 3 best policy/guidance documents, and is presented in Appendix 6. Appendix 7 provides a summary table of all the policies and legislation reviewed.

### **6.2. United Kingdom (UK)**

#### **6.2.1. Introduction**

Fifty-four UK policy documents were reviewed but only 27 policies relating to people with disabilities were considered relevant to this review. In the UK (as in Ireland), disability policy is seen as part of the equality and human rights agenda. The provision of health and medical care in the UK is similar to the public systems in

Ireland and Sweden, and there is almost no private practice. Services are provided free of charge and are funded by the taxation system and the provision of services for people with disabilities are considered to fall within the context of the general medical services. Local Authorities do provide specific support and social care services such as interpretation services and personal assistance; however, these services are subjected to means testing.

### **6.2.2. Legislation relating to people with disabilities**

Since the 1990s, many legislative instruments have shaped and influenced the provision of services for people with disabilities. The National Health Service and Community Care Act (1990) introduced the concept of assessment and care management for people with disabilities (UK Parliament, 1990), but this legislation has been exposed to many legal proceedings relating mainly to the funding allocated to local health authorities. Consequently, authorities introduced eligibility criteria and the rationalisation of resources for people with disabilities.

In 1995 the Disability Discrimination Act (DDA) was introduced and this was the first piece of legislation to recognise and advocate the social model of disability (UK Parliament, 1995). It is the foundation of disability policy in the UK and represents an extension of the civil rights of people with disabilities. Its provisions are applicable across England, Scotland, Wales and Northern Ireland. The key areas addressed within the Act include education, employment, transport, goods facilities, services and premises. The provisions of the Act require service providers to provide reasonable adjustment for women with disabilities in order that they can access services in an effective manner. This includes making alterations to buildings to ensure that they are physically accessible, changing policies, guidelines, procedures and practices to include people with disabilities and to provide auxiliary aids or services if required.

This Act was replaced by the Disability Discrimination Act 2005 (UK Parliament, 2005a). This act extends the definition of disability and affords greater protection for people with disabilities. Under this act service providers are required to be proactive

in the promotion of accessibility and equality for people with disabilities. The overarching principle is that people with disabilities have a fundamental right to have their needs for access to appropriate healthcare met. From December 2006, each primary care trust is required to publish a Disability Equality Scheme; this is a 3-year action plan outlining the actions to be undertaken in order to achieve disability equality and progress on the plans will be reviewed at 3-year intervals.

### **6.2.3. Policies relating to women with physical and sensory disabilities**

#### **6.2.3.1. National guideline documents**

In addition to the disability legislation, standards of care established under the National Service Framework and the National Institute for Health and Clinical Excellence, formerly the National Institute of Clinical Excellence, and those developed by professional bodies, all impact on the provision of services for women with disabilities. The National Institute for Health and Clinical Excellence is an independent organisation responsible for the development and publication of national guidelines to promote good health. It has produced 3 documents that guide practice and care in the antenatal, intra-partum and postnatal period. At present, none of these documents mention or discuss care in the context of women with physical or sensory disabilities; however, a guideline currently being developed to provide advice on the care of pregnant women with complex needs, for completion by 2010, may possibly include information relating to women with disabilities.

A 'good practice' document entitled 'Doubly Disabled: equality for disabled people in the new National Health Services (NHS): access to services' was issued in 1999 (UK Department of Health, 1999), within the legislative framework of the Disability Discrimination Act (UK Parliament, 1995; 2005a). The document provides guidance to senior managers of NHS services on what constitutes good practice and facilitates equality of access for people with disabilities. Although not specific to maternity services, some provisions of the document are relevant to women accessing the services during pregnancy, childbirth and early motherhood.

Within the guide the Liverpool Women's Royal Hospital is presented as an example of good practice. The hospital has appointed a disability advisor who assumes a supportive and advisory role for both women attending the services and all staff working in the organisation. In addition to providing information, advice and disability awareness and training to staff, the disability officer also acts as an advocate for women attending the services. The disability officer is responsible for the promotion of equality of access, service and care and provides support, advice and information to women with a disability. The guideline also presents practical recommendations on how to communicate effectively and appropriately with people with disabilities. The application and use of auxiliary aids are promoted and practical guidance on how to assist a person with a sensory impairment is provided (UK Department of Health, 1999). Since the document was published, a Milton Keynes Hospital has also appointed a disability advisor with similar roles and responsibilities as outlined above. These were the only 2 examples identified from the literature reviewed.

#### **6.2.3.2. Guidelines and standards from professional bodies**

Professional bodies such as the Royal College of Nursing and Royal College of Obstetricians and Gynaecologists have developed and published guidelines and clinical standards, which impact on the provision of care for women with disabilities. In particular, the Royal College of Obstetricians and Gynaecologists, in collaboration with the Royal College of Midwives, the Royal College of Anaesthetists and the Royal College of Paediatrics and Child Health, developed an agreed set of national standards for maternity care, extending from the preconceptual to postnatal period (RCOG, 2008). Existing evidence-based standards were reviewed, and key provisions were extracted and collated to produce this standard document, which contains 48 guidelines, only one of which refers to women with disabilities. It is, however, the first document that considers women with disabilities in the context of reproductive care.

Standard 3 addresses the issue of access to maternity care and indicates how local maternity services are responsible for ensuring inclusiveness of women with a learning and physical disability and that the services must address the individual communication, support and equipment needs of such women (Standard 3:3.9).

Standard 7 states that services must be innovative and flexible to address the individual needs of women with disabilities (Standard 7:7.4) and care should be delivered within a multi-agency team comprising of a specialist midwife and/or obstetrician (Standard 68:30.9). For women with a physical, cognitive or sensory impairment the method of communication employed and any information provided during pregnancy should be in an accessible and alternative format relevant to the individual's need (Standard 22:22.7). When developing, planning and implementing local maternity services and strategies, Standard 26 determines that consideration and account be taken of the available technological equipment and networks, local transportation services and the physical accessibility of the building, all of these impact significantly on the accessibility of services for women with disabilities (Standard 26:26.6) (RCOG, 2008).

The standards document reflects the content of a position paper published by the Royal College of Midwives in 2000. The position paper reiterated the importance of consulting with women when designing, planning and implementing maternity services for women with disabilities (RCM, 2000). It states that women should have access to accurate, accessible and appropriate information, parent education classes should be accessible, flexible and innovative and midwives must be aware of local supports and contacts in order to refer the women appropriately. A philosophy of women-centred care should be adopted and, to alleviate the prejudicial attitudes that exist, disability awareness and training for all staff is advocated.

In 2007, the Royal College of Nursing also designed and published guidelines to assist midwives and nurses in addressing the needs of a woman with a disability during pregnancy, childbirth and motherhood (RCN, 2007). The guidelines identify the midwives' responsibility under the various legislative instruments and promote the principles of equality, inclusiveness and non discrimination. They detail the correct and acceptable terminology that should be adopted and used during each interaction between the midwife and woman, and recommend effective and appropriate methods of communication. Knowledge and awareness of conditions and disability is described as essential in the assessment and planning of care. Midwives are advised to be aware of the specific and appropriate questions to ask in order to conduct an

appropriate and relevant assessment and to provide adequate, accurate information. A knowledge of where, and from whom, women may source information is stated to be critical, and midwives are advised to collaborate with, and utilise, these resources to increase their own knowledge base (RCN, 2007). It is recommended that an assessment of women's needs be conducted early in pregnancy so that referrals, if needed, may occur and suitable support structures can be established as early as possible. For example, antenatal care may be offered in the home or within the local community and any aids or equipment required for the birth can be organised well in advance. It is also stated that parent education classes should address the specific needs of this population and should provide referrals to appropriate parenting support groups and networks. The guidelines provide direction on how attitudes can be addressed through disability training and awareness, which may encourage midwives to embrace diversity and inclusiveness, encouraging women to remain independent and to become active participants in the planning and implementation of their care. The guidelines also provide practical guidance on how midwives can ensure that the physical environment is accessible and the communicational and information needs of women with disabilities are met in an effective, appropriate and accessible manner (RCN, 2007).

It was difficult to draw any conclusion of best practice due to a lack of research in this area, but the documents described above, produced by the 3 professional bodies (RCM, 2000; RCN, 2007; RCOG, 2008) are the best available. Information from these 3 documents has been compiled to provide a guideline exemplar, which is presented in Appendix 6.

## **6.2.4. Policies relating to women with mental health difficulties**

### **6.2.4.1. National guideline documents**

The National Institute for Health and Clinical Excellence care guidelines state that clinical networks should be instituted for perinatal mental health services (NICE, 2007). A co-ordinating board of healthcare professionals, commissioners, managers, service users and carers is recommended to manage the service. These groups



should provide a specialist multidisciplinary service for every area, providing direct care and consultation to maternity and community services and other mental health services. It is suggested that in localities with high morbidity, these services could be provided by specific specialist perinatal teams, with clear referral and management criteria to ensure effective transfer of information and continuity of care. It is recommended that each perinatal mental health network should have designated specialist inpatient services and should provide facilities specifically for mothers and babies. Women who require inpatient care within 12 months of childbirth should be admitted to a specialist mother and baby unit unless there are particular reasons for not doing so. The service should be staffed by an appropriate level of specialist perinatal mental health staff and liaise effectively with general medical and mental health services. Availability of the full range of therapeutic services, such as psychology, psychiatry, nursing, social work and psychotherapists, is recommended and the facility should be closely linked with community based mental health services to ensure continuity of care and minimum length of stay (NICE, 2007).

Regarding screening, the guidelines state that women should be questioned about past or present severe mental illness including schizophrenia, bipolar disorder, postnatal psychosis and severe depression, and family history of perinatal mental illness, during first contact with antenatal and postnatal services. The guidelines state that women should not be probed about specific prognostic factors, such as relationship problems in routine predictions of the development of mental illness. However, they should be asked whether they have felt low, depressed or hopeless during the past month or if they have taken little pleasure in daily activities, and if this is the case they should be asked if they need specific help; if psychological therapy is required they should have to wait no longer than 3 months for an appointment. The screening guidelines emphasised that maternity staff required training in order to implement screening sensitively (NICE, 2007).

The National Institute for Health and Clinical Excellence also emphasise the need for access to expert advice about the risks and benefits of psychotropic medication during pregnancy and breastfeeding. The detailed way in which health professionals are instructed to provide information about treatment, with audio recording of the

session, reflects serious concerns, particularly about the safety of anti-psychotic drugs (NICE, 2007).

The Scottish Intercollegiate Guidelines Network developed national clinical guidelines incorporating evidence based recommendations for effective practice in relation to postnatal depression and puerperal psychosis (SIGN, 2002). The guidelines are graded A, B, C, or D to signify the strength of the supporting evidence, with 'A' being based on the clearest evidence. The recommendation (graded as A) states that routine screening for a history of depression should be carried out during the antenatal period and all women should be screened (graded as D) for previous episodes of puerperal psychosis, particularly bi-polar disorder, and for a family history of these illnesses. The postnatal recommendations warn that natural emotional states may mask or be misinterpreted as depression, and that all women should be offered testing, at about 6 weeks and again at 3 months following childbirth, using the Edinburgh Postnatal Depression Scale, but the use of the Edinburgh Postnatal Depression Scale should not replace a clinical diagnosis of postnatal depression. These recommendations are substantiated by recent work that demonstrates that the Edinburgh Postnatal Depression Scale detects anxiety, but does not adequately distinguish between anxiety disorders and depression in postnatal mothers (Rowe et al, 2008). The guideline further states that the impact of postnatal depression on the whole family should be considered and suggest that high risk mothers may benefit from postnatal visits, psychological therapy and /or antenatal education, and that women with a high risk of puerperal psychoses should be reviewed by psychiatric specialists (SIGN, 2002).

The Scottish Intercollegiate Network puerperal psychosis guidelines (graded D) state that the disorder should be managed in the same manner as psychosis arising at any other time. The use of appropriate drug treatment during breast feeding and pregnancy should be considered. Specialist in-patient facilities should be available and mothers and babies should not be admitted to general psychiatric wards. The rest of the guidelines concern recommendations for prescribing anti-depressants. They state that there is no indication for stopping tricyclic or selective serotonin reuptake inhibitor (SSRI) antidepressants during pregnancy and there is no indication

that tricyclic anti-depressants, apart from Doxepin, should be stopped during breast-feeding (SIGN, 2002).

Major findings from the Confidential Enquiry into Maternal Deaths (CEMACH, 2004) underpin many of the clinical risk management guidelines such as those from the National Institute of Clinical Excellence (NICE, 2007). The report recommends that maternity services should follow risk management guidelines and include routine enquiries about previous psychiatric history at the antenatal booking clinic; the term postnatal depression should not be used as an umbrella term for all types of psychiatric illness and women with a past history of serious mental illness, whether or not associated with childbirth, should be assessed by a psychiatrist during the antenatal period because of the high risk of relapse after childbirth. The Confidential Enquiry into Maternal Deaths (CEMACH, 2004) supports the development of mother and baby units and suggested that the separation of mothers and babies might have contributed to maternal suicide, given that no deaths occurred in women admitted at any time to a mother and baby unit. The report also recommends that midwives provide active follow up for women at risk, who do not access regular antenatal care. The most recent Confidential Enquiry into Maternal Deaths (CEMACH, 2007) shows a decrease in maternal suicides and comments that if this decrease is maintained through the next triennial reporting period, it may be reasonable to assume that the developments outlined above have resulted in an improvement in the service provided.

#### **6.2.4.2. Guidelines and standards from professional bodies**

In 2000, the Royal College of Psychiatrists in England produced recommendations for perinatal mental health services. These recommendations influenced the development of the NICE (2007) and SIGN (2002) guidelines.

## 6.2.5. Policies relating to women with intellectual disabilities

### 6.2.5.1. National guideline documents

While the majority of UK social policy documents do not explicitly make reference to the maternity needs of women with intellectual disabilities, many do emphasise the need for health services to be more responsive to the needs of people with intellectual disabilities within the contexts of inclusion, equality of access, fairness and equity. The *Framework for Maternity Services in Scotland* (Scottish Executive, 2001), and *Promoting Health, Supporting Inclusion* (Scottish Executive, 2002), reflect a view that maternity and intellectual disability services should work in partnership, with an emphasis on multidisciplinary community services. *Promoting Health, Supporting Inclusion* (Scottish Executive, 2002) also acknowledges midwives' concerns regarding their lack of knowledge and clinical experience of caring for this group of women, but reminds them of their mandatory duties under professional registration and encourages the profession to develop their pre and post registration midwifery courses to address this. No specific reference to the maternity needs of women with intellectual disabilities was found in the key strategy and review documents from the 4 regions of the UK: *Valuing People* (UK Department of Health, 2001); *The Same as You?* (Scottish Executive, 2000b); *Fulfilling the Promises* (Welsh Assembly, 2001); *Equal Lives* (UK Department of Health, Social Service and Public Safety, 2004) and *The Bamford Review* (UK Department of Health, Social Service and Public Safety, 2007).

The Secretary of State for Health (2004) emphasises the need for some women with intellectual disabilities to have access to independent advocates when they are reporting domestic violence or discussing mental health issues when receiving maternity care. Midwives are reminded that it is not best practice to use the patient's family or friends in this role. The Secretary of State for Health (2004) also highlights the need for 'fully accessible' information to be available to all women with disabilities, including women with intellectual disabilities.

### 6.2.5.2. Guidelines and standards from professional bodies

The Royal College of Midwives' position paper *Maternity Care for Women with Disabilities* (RCM, 2000) acknowledges the specific maternity care needs of women with intellectual disabilities but does not proceed to identify what those needs are or how they may be best met, addressing disabled women generically, as a homogeneous group. While each of the issues raised may apply to women with intellectual disabilities, some, such as informed consent, may not be equally applied to this group, for it is suggested that some such women may not be able to give full or partial consent to treatment (UK Department of Health, 2001; RCN, 2006). No solutions are proffered to address this issue legally, and no reference is made to the various consent legislations such as the *Mental Capacity Act 2005* (UK Parliament, 2005b) or the *Adults with Incapacity Act 2000* (Scottish Executive, 2000a).

No reference was found in the RCN's document *Meeting the Health Needs of People with Learning Disabilities* (RCN, 2006) to the maternity needs of women with intellectual disabilities. The following year, the Royal College of Nursing published *Pregnancy and Disability* (RCN, 2007), which offers limited insight into the needs of women with intellectual disabilities accessing maternity care. This advisory document acknowledges that these women may become pregnant and need to access maternity services. It encourages maternity professionals to work collaboratively with their counterparts in the intellectual disability field and to approach carers and family members to identify means of communicating with the woman with intellectual disabilities, rather than encouraging client empowerment and self advocacy, which would be considered the norm by professionals working in the intellectual disability field.

### 6.2.6. Recent National Health Service reform

The National Health Service has recently undergone a period of reform and is committed to using available resources in an effective and fair manner in order to reduce inequalities and deliver a safer and better healthcare system. The government guaranteed that women and their partners would, by the end of 2009, have choices in respect of how to access maternity care, type of antenatal care,

place of birth and place of postnatal care. In 2004, a guidance document entitled 'National Service Framework for Children, Young People and Maternity Services' was published, which establishes standards for the promotion of health and well-being of mothers and the provision of a high quality service to address individual needs (UK Department of Health, 2004a). Standard 11 of this document focuses on the development of an accessible, supportive quality maternity service planned around women's individual needs. Recognising that women with disabilities often feel excluded and disconnected from the services, actions to ensure more inclusiveness are proposed. They require service providers to undertake a commitment to improve access to maternity services and ensure services are effective and responsive to the needs of women from disadvantaged and minority groups, and recommend that service design and planning should address challenges and barriers that women with disabilities may encounter when accessing care. Specific reference is made to women with physical and intellectual disabilities, and service providers are advised to ensure that local maternity services are inclusive and that attention is given to women's communication, equipment and support needs. The strategy does not attempt to extrapolate what the actual needs of women with intellectual disabilities are, or how best they might be met, but it does acknowledge difficulties in gathering data on groups with disabilities. The strategy also identifies the need for partnership between maternity and intellectual disability services, suggesting that multidisciplinary community intellectual disability teams would be key in achieving this. It is recommended that the need for a translator, interpreter or advocate should be determined on an individual basis and, if required, their services should be engaged.

Based on these guidelines, the UK Department of Health produced a document entitled 'Maternity Matters: choice, access and continuity of care' (UK Department of Health, 2007) to improve choice, access and care for all women requiring maternity services. The policy identifies how maternity services must be planned in order to address the many challenges, which include improving the outcome for vulnerable and disadvantaged groups. It sets out a commitment that maternity services will be accessible to all women and planned around individual needs, including those related to disability. Adapting antenatal and postnatal care to individual needs will require the

development of outreach maternity support programmes and accessible community facilities. To facilitate and support informed decision, the policy commits to ensuring information about the services and models of care provision will be accessible and available in alternative formats. Although vulnerable groups are identified, there is no specific reference made to women with disability in this policy (UK Department of Health, 2007). It is also interesting to note that, although the National Health Service is publicly-funded, no evidence was found of a national service framework for people with intellectual disabilities.

## **6.3. The Netherlands**

### **6.3.1. Introduction**

In the Netherlands maternity services and care fall within the remit of primary healthcare. The Dutch healthcare system is funded by the national insurance system and is delivered by both statutory and non statutory agencies. Non discrimination, participation and inclusiveness are the principal foundations of the Dutch approach to people with disabilities.

### **6.3.2. Legislation relating to people with disabilities**

The Netherlands adopted the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities and implemented them through the provisions of the Act on Facilities for the Disabled in 1994. Equality is also enshrined in the Dutch constitution and, similar to other countries reviewed, discrimination on the grounds of disability is prohibited. The Equal Treatment on the Grounds of Disability or Chronic Illness Act (Ministry of Health, Welfare and Sport, 2003) reinforces the person's right to equality and the prohibition of discrimination on the basis of disability. Enacted in 2003, the provisions of the Act apply to specific areas, namely employment, public transport, vocational and professional education; they have no remit in the health sector.

### **6.3.3. Policies relating to people with disabilities**

The Netherlands has a well-developed policy on disability employment. The Ministry of Health, Welfare and Sport is currently developing a health policy that will be responsive to the needs, and inclusive, of people with disabilities. The provisions of the Equal Treatment on the Grounds of Disability or Chronic Illness Act (Ministry of Health, Welfare and Sport, 2003) do not apply in the health sector; however, monetary assistance is provided to aid in the provision of personal assistants and home care for people with a physical, sensory or intellectual disability. An Action Plan was published by the Ministry of Health, Welfare and Sport in August 2004 that outlined the rights and expectations of people with disabilities when accessing all facilities in the country (Ministry of Health, Welfare and Sport, 2004). In April 2007, however, the Dutch Coalition on Disability and Development (DCDD) conducted a survey of 24 non-Governmental organisations in the Netherlands and found a continuing lack of attention to disability issues in their policies and practice (DCDD, 2007). Just under 2 years later, in early 2009, the DCDD noted that the Government had now pledged to make special efforts for groups such as people with disabilities, whose voices, they acknowledged, had not been heard sufficiently in the past (DCDD, 2009).

## **6.4. Sweden**

### **6.4.1. Introduction**

Sweden's 290 municipalities are responsible for the provision of care for all people accessing the health services. Swedish health and social services, like Ireland, the UK and Canada, are funded from tax revenues and are governed by the provisions of the Social Services and Health Care Act. The Swedish National Board of Health and Welfare is responsible for the provision of medical and social care and to date have developed guidelines in areas such as coronary heart disease, stroke and diabetes mellitus, but none in relation to disabilities.



#### **6.4.2. Legislation relating to people with disabilities**

Legislation prohibiting discrimination on the grounds of disability was introduced in 2003. Section 9 of the Prohibition of Discrimination Act (Government of Sweden, 2003) determines that discrimination on the basis of disability is prohibited in connection with the professional provision of services. Provisions of the Support and Service for Persons with Certain Functional Impairments Act (Ministry of Health and Social Affairs, 1994) can be implemented to enhance support for women with disabilities. The Act applies to people with extensive disabilities, affording them a greater opportunity to lead an independent life and to participate fully in society. It legislates for the availability and appointment of support structures such as personal assistance, counselling, modified housing and support for the parents of children with disabilities. The provisions of this law do not apply to all people with disabilities.

#### **6.4.3. Policies relating to women with physical and sensory disabilities**

The Swedish disability policy 'From Patient to Citizen' (Ministry of Health and Social Affairs, 2001) was the first public policy document targeted at people with disabilities. The main objective of the plan, which extends to 2010, is to reform society's attitudes towards and acceptance of people with all disabilities. It aims to identify and remove the obstacles that prevent people with disabilities from participating in society and to prevent and overcome discriminatory practices experienced by people with disabilities. The main pillars of the policy are education and employment.. Accessibility to the built environment is deemed to be an area requiring action. Obstacles that impede physical accessibility and functionality of people with disabilities are to be removed by 2010 and to assist in this goal the National Board of Housing, Building and Planning are to give priority to issues of accessibility for people with disabilities and to clarify the requirements of existing legislation to ensure accessibility in new buildings and alternation/renovations to existing buildings (Ministry of Health and Social Affairs, 2001). The policy recommends that people with disabilities should be consulted when determining the regulations to facilitate accessibility.

The Swedish agency for disability policy coordination, Handisam, was tasked with responsibility to coordinate and implement the disability policy. It subsequently

developed and published a generic guideline on accessibility, which employers are required to adapt in order to address their obligations within disability policy (Handisam, 2004).

## 6.5. Norway

### 6.5.1. Introduction

All Norwegian women are entitled to free maternity care, with 99% availing of this, and this care is mediated via 'decentralised and differentiated ante/postnatal' services (Norwegian Ministry of Health and Care Services, 2007a:55), with continuity of care and safety of mothers paramount. These principles are consistent with the stated value of 'equality of access for all' which underpins Norwegian health policy (Norwegian Ministry of Health and Care Services, 2007a:55).

### 6.5.2. Legislation relating to people with disabilities

Two key pieces of Norwegian legalisation were sourced – The Act of 2nd July 1999 No. 63 relating to Patient's Rights (the Patients' Right Act) (Norwegian Ministry of Health and Care Services, 1999a) and the Act of 2nd July 1999 No 64 Relating to Health Personnel (The Health Personnel Act) (Norwegian Ministry of Health and Care Services, 1999b). Neither of these Acts refers specifically to people with disabilities but the provisions within the Acts have the potential to impact on the healthcare accessed by these people. The Patient's Rights Act (Norwegian Ministry of Health and Care Services, 1999a) affords all citizens in Norway specific rights such as the equal access to quality healthcare and the promotion of a trusting relationship when the person is interfacing with the health services. It provides for the right to access care, the right to participation in planning their care and obtaining information about their care and treatment; it addresses the issue of consent, the right of access to medical records and the special rights of children. However, people with disability are not mentioned.

The Health Personnel Act (Norwegian Ministry of Health care Services, 1999b) applies to all health professionals and healthcare providers and it has 2 core objectives - the safety of patients and quality within the health services. It mandates on the professional conduct, organisation of facilities; confidentiality and the right of discourse; documentation and notification requirements; training and regulation of specialist training for health professions. Again, there is no specific reference to people with disabilities but the provision of the Act will protect these individuals when accessing health services in Norway.

Accessibility to the built environment is regulated by the Programme of Action for Universal Design (Norwegian Ministry of the Environment, 2003) and provisions of the Norwegian Discrimination and Accessibility Act (Norwegian Ministry of Health and Care Services, 2009). The Act sets out the requirements to ensure universal design of environments and accessibility of workplaces, schools and day care centres. The objective of the Programme for Action for Universal Design was to increase and ensure equality in access to public spaces for people with disabilities. Subsequently the Delta Centre, the national resource centre for participation and accessibility for people with disabilities, published guidelines in relation to Universal Design. The guidelines, based on 7 principles, are a mechanism of avoiding discrimination for people with disabilities and advocate that all environments, information and services be designed in such a way that they are accessible and usable by everyone. The guidelines encourage the embracement of diversity and their primary objective is to afford people with disabilities equal opportunities and the ability to participate fully in society (Delta Centre, 2009).

### **6.5.3. Policies relating to women with physical and sensory disabilities**

Specific Norwegian policies relating to the care of women with physical and sensory disabilities were not identified by the team. In the preamble to the National Health Plan 2007-2010 (Norwegian Ministry of Health and Care Services, 2007a), the Ministry of Health acknowledge that the goals therein are ambitious but should be achievable. It is envisaged that the 4-year plan will result in a high quality public service accessible to all regardless of social status, gender, age, economic status

and ethnic background. Disability is not mentioned specifically. One strategic objective is equal access for all people regardless of where they live, but again disability is not highlighted.

The plan outlines how maternity care for pregnant women will be delivered from public health centres located locally and resourced by a multidisciplinary team comprising of midwives, physicians and physiotherapists, thus ensuring good proximity of services for all women. The Ministry recognise that some individuals will require the services of an advocate and have undertaken measures to address this including a proposal to amend the law regulating advocacy services in order that people attending municipal health services will have access to an advocate. Referring to people with disabilities, the plan notes how this is not a homogeneous group and indicates the importance of providing accessible health services for these clients. It determines that accessibility encompasses more than just access to the physical built environment it also includes transport, communication and information, and equitable access to care is promoted. Currently, legislation in the form of the Planning and Building Act is being drafted to regulate accessibility to the built environment and the Ministry of Health is participating in the consultation process (Norwegian Ministry of Health and Care Services, 2007a).

#### **6.5.4. Policies relating to women with mental health difficulties**

Johnsen (2006) reviewed the Norwegian Mental Health system for the WHO but did not make reference to perinatal mental health policy. An extensive search failed to find any relevant policy documents.

#### **6.5.5. Policies relating to women with intellectual disabilities**

Norway has seen a significant shift in social policies relating to persons with intellectual disabilities during the past century, during which time the country moved from a strong eugenic stance grounded in the practice of sterilisation, to embrace the tenets of normalisation and social role valorisation that had been developing in Denmark and Sweden (Roll-Hansen, 2005; Race, 2007). Despite this paradigm shift, this review found little information of relevance to the maternity services for women

with intellectual disabilities. The 2 principal documents examined were the National Health Plan for Norway 2007-2010 (Norwegian Ministry of Health and Care Services, 2007a) and the Minister for Health and Social Care's proposals, entitled 'Proposition to the Storting No. 1 (2006-2007) Chapter 6: National Health Plan,' to the Norwegian Parliament for that National Health Plan (Norwegian Ministry of Health and Care Services, 2007b).

Through the National Health Plan for Norway (2007–2010) the government is committed to developing a fairer and more equal provision of healthcare. The plan highlights the need for greater patient involvement in the development of health services (including maternity care). Whilst it acknowledges that some people with intellectual disabilities may not be best able to ensure that their needs and rights are fully met, it encourages greater involvement of relatives as advocates and promotes the role of patient organisations in policy and service development.

The Ministry of Health and Care Services also recognises the limited knowledge base of many health and social care professionals in meeting the care needs of people with intellectual disabilities and has therefore instructed the Directorate for Health and Social Affairs to carry out a review of services to identify specific issues needing to be addressed (Norwegian Ministry of Health and Care Services, 2007b). At this point the review will not consider the specific needs of women with disabilities (Norwegian Ministry of Health and Care Services, 2008).

## 6.6. Denmark

### 6.6.1. Introduction

Denmark is primarily a welfare state and the country is divided into 14 counties with 275 local authority districts (Danish Disability Council, 2002). Since 1970, Denmark has witnessed significant reform in the disability sector and the core objective of the Danish disability policy is equalisation of opportunities for all people with disabilities.

In 1993, the Danish government adopted the UN Standard Rules on the Equalisation of Persons with Disabilities.

### **6.6.2. Legislation relating to people with disabilities**

Following the adoption of the UN Standard Rules, the parliament adopted and enacted the B 43, a parliamentary resolution concerning equalisation of opportunities for disabled and non disabled persons (Danish Disability Council, 2002). This parliamentary Act is founded on the principles of integration and normalisation and establishes that all public and private authorities should enforce the principle of equal rights and the equality of opportunities for people with disabilities. The disability policy in Denmark is built on 3 critical concepts: an environmental based perception of disability, the principle of compensation and the principle of sector responsibility (Danish Disability Council, 2002). Essentially, an environment-based perception of disability is akin to adopting the philosophy enshrined in the social model of disability, as it situates the disability within the context of the environment rather than the individual. Following on from this approach, the principle of compensation implies that services and aids are available and accessible to people with a disability in order to ameliorate the disability. Each authority is responsible for ensuring equality of opportunities for people with disabilities but enforcement of the resolution and mandating accountability is hampered by the fact that the resolution is not legally binding.

Essentially Danish disability policy is an amalgamation of various pieces of legalisation. With respect to accessibility, building regulations (Ministry of Housing and Urban Affairs, 1999) establish measures that must be addressed in new, or renovations of, small and large buildings to afford people with disabilities access to the physical environment. Measures within the legislation also provide for the installation of an induction loop system to facilitate effective communication for people who are deaf (Danish Disability Council, 2002). People with disabilities are entitled to auxiliary aids and services including home help to ameliorate the effects of disability (Danish Disability Council, 2002).

### **6.6.3. Policies relating to women with physical and sensory disabilities**

No specific policies were sourced in relation to women with a physical or sensory impairment. However, while making no specific reference to maternity policy for women with disabilities, the July 1998 Act No. 428 on patients' rights provides for the rights of all patients to 'integrity, dignity and self determination' (Government of Denmark, 1998).

### **6.6.4. Policies relating to women with mental health difficulties**

In 2002, the Danish Government recommended early interventions for postpartum depression and emphasised the need to protect the mother child-relationship. Health promotion initiatives for all pregnant women with special interventions for the vulnerable and distressed are advocated, with no specific details about what these approaches should be. Early detection, treatment and support are advocated for vulnerable and distressed groups of women with the aim of protecting the child during the pregnancy and ensuring care after the birth. The document also stated that experience had demonstrated that many of these women can be targeted through interdisciplinary teams or family clinics by specialist staff (Government of Denmark, 2002).

## **6.7. New Zealand**

### **6.7.1. Introduction**

It is estimated that about 1 in 5 New Zealanders have a disability (New Zealand Ministry of Health, 2008a). The provision of health services and disability support services for these people are provided for within the various provisions of the New Zealand Public Health and Disability Act (Government of New Zealand, 2000).

### **6.7.2. Legislation relating to people with disabilities**

Part 2 of the New Zealand Public Health and Disability Act prescribes that the Minister of Health must devise a strategy for health that will become the framework for improving the health of all New Zealanders (Government of New Zealand,

2000:17). Likewise the Minister of the Crown who has responsibility for disability issues must 'develop a strategy for disability support services to provide the framework for the government's overall direction of the disability sector in improving disability support services' (Government of New Zealand, 2000:17). Both these strategies can be amended or replaced at any time. During the development period of both strategies the Act specifies that the relevant Minister must consult with all key stakeholders.

### **6.7.3. Policies relating to women with physical and sensory disabilities**

#### **6.7.3.1. National guidelines and strategies**

Health and disability services in New Zealand are guided by 2 interlinked social policies: the New Zealand Disability Strategy (New Zealand Ministry of Health, 2001a) and the New Zealand Health Strategy (New Zealand Ministry of Health, 2000). The New Zealand Health Strategy identifies the priority areas that need to be addressed to achieve the objective of an equitable and fair health service for all. The strategy sets out 10 goals and 61 objectives. None of these refer specifically to women with a physical or sensory disability. Goal 10 of the strategy sets out a commitment that all people in New Zealand will have accessible and appropriate healthcare services, and specific reference is made to maternity and child care services. In addition to access to appropriate primary care, maternity care, public health services and child care services, the strategy establishes a commitment to ensure the services are women focused, that information about the services is accessible to all users and that care will be delivered in a 'clinically sound, culturally competent and well co-ordinated' way (New Zealand Ministry of Health, 2000:25).

The New Zealand Disability Strategy was introduced in 2001 and was heralded as a visionary document that facilitates inclusiveness and participation of people with a disability in a non disabling society. Within the 6 years since its introduction, New Zealand has undertaken a number of other measures to advance the rights of people with disabilities. These include becoming a signatory to the United Nations Convention on the Rights of Persons with Disabilities. The Disabled Persons



Employment Promotion Act and the New Zealand Language Act were enacted into law and the last institutions for people with physical and intellectual disabilities were closed.

The disability strategy, based on the social model of disability, sets out 15 objectives for people with all disabilities (New Zealand Ministry of Health, 2001a). Objective 14 is the only one to refer to women with disabilities and it focuses on improving their opportunities to access appropriate disability services (not maternity services) that will enhance their quality of life.

One year after the introduction of the New Zealand Health Strategy, the Primary Care Health Strategy (New Zealand Ministry of Health, 2001b) was developed. The vision espoused in the strategy is that local primary care services will be accessible, coordinated and will address the needs of a defined population. Barriers to accessing primary healthcare services will be identified and facilitators implemented.

Information about the services and on how to access them will be provided in written, oral and electronic format and available in different languages and formats. Where persons are unable physically to access the services, the service providers are encouraged to explore the possibility of providing services in alternative settings including people's own homes or workplace. Service providers are required to consult with disability organisations to identify and implement facilitators that will ameliorate any physical, psychological and communication barriers experienced by people with disabilities. The Sexual and Reproductive Health Strategy (New Zealand Ministry of Health, 2001c), recognising the particular problems encountered by people with disabilities in accessing mainstream sexual and reproductive health services, mandates for primary and specialist health services to be accessible and responsive to the diverse needs of people with disabilities.

In 2004, the Ministry of Women's Affairs launched their Action Plan for New Zealand Women (New Zealand Ministry of Women's Affairs, 2004), which set out a number of measures to improve the quality of life of New Zealand women. One measure was the improvement of women's health and well-being, more specifically mental health and sexual and reproductive health. The policy notes how for women with disabilities

their inability to access services can significantly impact on their well-being. The plan establishes an objective to improve access to services, including mental health services, for women with disabilities; however, how this is to be achieved is not discussed.

#### **6.7.4. Policies relating to women with mental health difficulties**

##### **6.7.4.1. National guidelines and strategies**

The Ministry of Health evaluated the first 9 months of a National Depression Initiative in 2008 (New Zealand Ministry of Health, 2008b). Pregnant women and those with new babies were targeted by the campaign, which involved advertising, a free phone service, websites, project management support and media coverage. The aspect of the review associated with postnatal depression concluded that midwives, as the main caregivers, have most contact with women before and after childbirth; consequently, the review recommended that they are best placed to monitor and advise women about postnatal depression.

##### **6.7.4.2. Guidelines and standards from professional bodies**

The Royal Australian and New Zealand College of Psychiatrists drew up a perinatal mental health plan in 2005, which focuses on depression. The plan states that anti-depressant treatment should continue throughout the pregnancy (Royal Australian and New Zealand College of Psychiatrists, 2005). Following birth, it is recommended that the mother should be cared for in a single room in the postnatal ward and should be allowed to sleep whenever feasible. She should stay on the postnatal ward for as long as possible so that she can be given enhanced support in establishing feeding and her mood can be observed. An assessment by the mental health team prior to discharge from the postnatal ward, or a priority outpatient appointment, is also recommended. It is stated that the baby should stay in the postnatal ward for 3 days and be monitored for signs of withdrawal from medication that the mother had been taking, and that an assessment by an on call paediatrician during this time may also be necessary. The plan should be copied to: the mother, the General Practitioner, the

obstetrician, the hospital file, the neonatologist and the psychiatrist (Royal Australian and New Zealand College of Psychiatrists, 2005).

A college statement by The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (2007) asserts that all maternity staff are responsible for identifying symptoms of depression during pregnancy that may indicate the development of postnatal depression. Staff may use screening tools and assess women for an individual or family history of postnatal depression or anxiety. It is stated that the identification of risk factors for postnatal depression should prompt maternity to staff to draw up a care plan so that the danger of postnatal depression is assessed and early intervention is initiated following delivery. (Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2007).

## **6.7.5. Policies relating to women with intellectual disabilities**

### **6.7.5.1. National guidelines and strategies**

Similarly to Irish and UK legislation, the sexual rights of women with disabilities are restricted by criminal law, namely the Crimes Act 1961 (Government of New Zealand, 1961), which deals with the sentencing of individuals who have exploitative sexual relations with people with significant impairment. The Health and Disability Commissioner has requested parliament to review this in the light of women's rights (Health and Disability Commissioner, 2004). In this context, it is interesting to note that the Disability Strategy is not law but is, rather, aspirational (Race, 2007).

A review of social policy documents revealed no explicit references to women with intellectual disabilities and maternity care. Neither the Disability Strategy (New Zealand Ministry of Health, 2001a) nor the Health Strategy (New Zealand Ministry of Health, 2000a) contribute greatly to the discussion of maternity care for persons with intellectual disabilities and the Disability Strategy Implementation Review 2001-2007 (New Zealand Office for Disability Issues, 2008) has not developed this position either.

The Health Strategy (New Zealand Ministry of Health, 2000) expresses an aim to ensure accessible and appropriate maternity care for all, while the Disability Strategy makes a commitment to ensure accessible and appropriate maternity care (New Zealand Ministry of Health, 2001a). Women with intellectual disabilities are not explicitly mentioned in The New Zealand Health Strategy (New Zealand Ministry of Health, 2000) but can be assumed to be included within the definition of disability i.e. 'Incapacity caused by congenital state, injury or age-related condition expected to last 6 months or more. A disability may or may not be associated with the need for assistance' (New Zealand Ministry of Health, 2000:48).

The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (Government of New Zealand, 2003) provides a legislative framework for meeting the needs of people with intellectual disability who been charged with or convicted of an imprisonable offence whether or not they are subject to the criminal justice system. Neither the act nor the guidance accompanying it (New Zealand Ministry of Health, 2004a; 2004b; 2004c; 2004d) explicitly make reference to maternity care. Guidelines do exist for the assessment of the cultural needs of Māori women/mothers with intellectual disabilities (New Zealand Ministry of Health, 2004d), which is to be commended, but no specific guidelines or protocols were found in relation to the maternity care of women and mothers in this context, nor is there any mention of intellectual disabilities within the Māori Health Strategy (New Zealand Ministry of Health 2002a). No specific reference is made to intellectual disabilities within the Pacific Health and Disability Action Plan (New Zealand Ministry of Health 2002b).

There is evidence that the needs of parents with intellectual disabilities are beginning to be addressed, albeit on a small scale, with a pilot service being developed by the Ministry of Social Development to help parents with intellectual disabilities to retain or recommence caring for their children (New Zealand Office for Disability Issues, 2008). Furthermore, a child, youth and family plan is being developed to create a pilot support service for parents with intellectual disability and to foster leadership development amongst them (New Zealand Office for Disability Issues, 2008).

## **6.8. Australia**

### **6.8.1. Introduction**

Like Ireland and New Zealand, Australia's disability policy is contextualised within its disability strategy (Australian Government, 1994). Thirty-two documents relating to disability, women's health and maternity care were sourced and reviewed. Eight were considered relevant, the provisions of which are discussed here.

### **6.8.2. Legislation relating to people with disabilities**

The legislative framework that underpins the strategy is the Disability Services Act (Australian Government, 1991), which was founded on the principles of dignity and equality, and legislates for respect for the rights and opportunities of people with disabilities. The Commonwealth Disability Discrimination Act (CDDA) was introduced in 1992 (Australian Government, 1992), amended in 1999, and underwent a comprehensive review in 2004. This Act is a rights based instrument and implementation of its provisions is the responsibility tasked to the human rights and equal opportunity commission spearheaded by the Disability Discrimination Commissioner. The CDDA sets out that people with disabilities have the right to the same opportunities, to access and to participate in all aspects of community life, including access to health services, as non disabled people.

In addition, the governments of all states and territories were required to introduce their own area-specific disability services legislation (Australian Government, 2008). For example, in Queensland, the Queensland Disability Act (Queensland Government, 2006) replaced the Services Disability Act (Australian Government, 1991) and the Intellectual Disabled Persons' Act (Government of Victoria, 1986). The Act is guided by human rights principles and provides a reform structure for the provision of quality services for people with disabilities. Section 7 of the act refers to the provision of accessible information and requires that information provided to people with disabilities is in an appropriate and accessible format and language.

### **6.8.3. Policies relating to women with physical and sensory disabilities**

#### **6.8.3.1. National guideline and strategy documents**

Born out of 5 principles, equity, inclusion, participation, access and accountability, the Commonwealth Disability Strategy (CDS) was introduced (Australian Government, 1994) as a framework to assist organisations to meet their obligations set out in the Commonwealth Disability Discrimination Act (Australian Government, 1992).

Essentially the CDS provides practical guidance to organisations on the removal of barriers, ensuring that the services, facilities and programmes offered by them are accessible to people with all types of disability, not physical and sensory alone, and all government departments and statutory agencies are expected to comply with its requirements. The strategy was evaluated in 1999 (Department of Housing, Families, Community Services, and Indigenous Affairs (FaHCSIA), 1999) and consequently a revised CDS was introduced in 2000 (Australian Government, 2000). The strategy underwent a second evaluation in 2006 (Erebus, International 2006), which revealed that positive outcomes have been achieved since the revised edition in 2000; however, the review also identified how people with disabilities from rural, non English-speaking and the indigenous population still encounter many disadvantages.

#### **6.8.3.2. Guideline documents of South Australia**

In South Australia, all government departments and agencies are required to develop disability action plans in order to meet their obligations established in the Commonwealth Disability Discrimination Act (Australian Government, 1992). The South Australian Health and Disability Action Plan (2008-2013) recognises and promotes an awareness of the rights, needs, potential and important contribution that people with disabilities can make to the community and wider society (Australian Government, 2008). The plan supports access and equity for all persons with disabilities, sets out measures to ensure that the physical environment is accessible and provides for access to information and communication in alternative and appropriate formats. No reference is made to women with disabilities, or their maternity or early motherhood care needs.

In March 2005, the South Australian Women's Health Policy was launched with the ultimate aim of improving the health of all South Australian women (Australian Department of Health, 2005). The policy coincided with the government's health reform programme, the core objective of which was the provision of services at local level, the strengthening of primary healthcare and the improvement of health services for the most vulnerable. The women's health policy requires health service providers to ensure that women with disabilities have access to the full range of 'culturally appropriate, sensitive and safe services' (Australian Department of Health, 2005:13). All health services are expected to identify and eliminate practices that can be considered discriminatory and policies, programmes and facilities should be redesigned to ensure that services are accessible for women with disabilities. Under the provision of the policy, service providers are obliged to ensure that services provided during pregnancy; birth and early motherhood to all women are consistent, comprehensive, well co-ordinated, women-centred, flexible and safe. The policy further states that all women, including women with disabilities, should have access to information on reproductive issues and practical parenting assistance.

#### **6.8.3.3. Guideline documents of the State of Queensland**

The Queensland Minister of Health established a review group in July 2004 and the terms of reference included an examination and review of services for pregnancy, birth and postnatal care across Queensland and to recommend evidence based strategies that would provide and enhance choices for women (Hirst, 2005). The review revealed that services are not responsive to women with special needs, including those with a disability. The review recommends the development of a new framework for maternity services based on the principles of empowerment, accessibility, inclusiveness and participation, but no specific strategies were proposed for women with disabilities (Hirst, 2005).

The Queensland Health Disability Service Plan 2007-2010 (Queensland Government, 2007a) was then developed by the Department of Health to address its obligations set out in the Commonwealth Disability Discrimination Act (Australian Government, 1992) and the Queensland Disability Services Act (Queensland Government, 2006). In its Queensland Health Strategy Plan 2007-2012 (Queensland

Government, 2007b), the Department of Health state that its goal is to provide sustainable services, safely and effectively, in a way that responds to the needs of all, including people with disabilities. The service plan is not gender-specific nor does it discuss reproductive or sexual health services. However, in terms of general health services, the service plan sets out numerous actions to be completed by 2010, including an action to improve physical access to the built environment for people with disabilities. (Queensland Government, 2007b).

#### **6.8.3.4. Guideline documents of the State of Victoria**

For women living in Victoria, section 8 of the Victorian Charter of Human Rights and responsibilities provides protection for the recognition and equality of individuals. It affirms that every person, regardless of gender or ability, has the right to embrace and enjoy their human rights without discrimination (Victorian Equal Opportunity and Human Rights Commission, 2008). Priority Strategy 5 of the Victorian State Disability Plan 2002-2012 (Victorian Government Department of Human Services, 2002a) sets out the government's commitment to making health services accessible and more inclusive. How this will be facilitated is not discussed apart from a general statement that health professionals will be more responsive to the health needs of people with a disability during all life cycles. The Victorian Women's Health and Wellbeing Strategy 2002-2006 (Victorian Government Department of Human Services, 2002b) outlines the government's strategic direction for the improvement for all women, especially disadvantaged groups. Guided by the principles of equity, recognition of diversity, consultation and participation, partnership and accessibility the strategy refers to women with disabilities. Acknowledging that these women can be one of the most disadvantaged groups in society, the strategy identifies the importance of providing accessible health information and services for this population.

#### **6.8.3.5. Guideline documents of the Australian Capital Territory (ACT)**

Composed following a consultative process, the ACT Women's Plan (ACT Office for Women, 2004) establishes an overarching objective to improve the quality of life for women in ACT. It provides the framework whereby priorities can be determined and strategies developed to improve the lives of all women, including those with a disability. The Plan sets out 6 objectives none of which refer specifically to



reproductive rights or sexual health. The Plan does refer to women with physical disabilities in the context of accessible built environment, but this is the only reference to this cohort. (ACT Office for Women, 2004).

#### **6.8.4. Policies relating to women with mental health difficulties**

The Australian Capital Territory Mental Health Strategy and Action Plan identified perinatal mental health as a key issue (ACT Mental Health Policy Unit, 2006). The Perinatal Mental Health Initiative provides screening and assessment of psychosocial risk factors for depression and provides information for women, families and primary health providers (ACT Mental Health Policy Unit, 2006). In 2003, Austin observed that perinatal mental health care remained patchy and difficult to access, but that innovations in public health policy and new models of service provision were reducing these deficiencies (Austin, 2003). Since then the Australian Government has supported a nationwide action plan to tackle all forms of depression, including antenatal and postnatal depression. This process was developed by *Beyondblue: the national depression initiative* in conjunction with a group of perinatal mental health experts (Beyond Blue, 2007). The plan incorporates pathways to care and education of all relevant health professionals, with the aim of ensuring that women experiencing perinatal depression receive relevant information and prompt professional interventions.

#### **6.8.5. Policies relating to women with intellectual disabilities**

Little or no state policy could be found that related specifically to maternity care for women with intellectual disabilities. Burgen (2007) suggests that the Children, Youth and Families Act, 2005 (Parliament of Victoria 2005) reflects the emerging policy perception that people with intellectual disabilities are unable to parent adequately. This concern may also be reflected in the identification of intellectual disabilities in the parents as a risk factor for the child in a maternity service communication protocol (Victorian Government Department of Human Services, 2004). There is much focus in the Australian literature on the rights of women with disabilities and in particular, on the history of forced sterilisation. Much of this literature has emanated from the non-governmental human rights group 'Women with Disabilities Australia'

(WWDA), an organisation that advocates for the rights of women with disabilities. The WWDA recently produced a policy paper entitled *'The Role of Advocacy in Advancing the Human Rights of Women with Disabilities in Australia'* (WWDA, 2008), drawing on the work of CEDAW (UN, 1979) and the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006). The paper highlights principal human rights for women with disabilities including 'motherhood, sexuality and reproductive rights' (WWDA, 2008:12). Recognising the almost systematic removal of children from mothers with intellectual disability (with decisions made even before the birth), the paper advocates accessible services to support parents whilst calling for law reform and a public inquiry into the treatment of these women. In respect of motherhood and parenting, the WWDA recommend the establishment of a 'National Resource Centre for Parents with Disabilities' (WWDA, 2008:18) addressing issues from pregnancy to motherhood.

#### **6.8.6. Recent national reforms and future developments**

In its position paper described above, Women with Disability Australia (WWDA, 2008) identify how disability advocacy can be used as a mechanism to advance and promote the human rights of women with disabilities. Disability advocacy is a relatively new concept but is beginning to be integrated into policy documents from various government departments including the Commonwealth Department of Families, Housing, Community Services and Indigenous Rights (WWDA, 2008). This department funds a range of disability advocacy models through the National Disability Advocacy Program but, to date, none of these models have been implemented for women during pregnancy, childbirth and early motherhood. WWDA propose establishing a resource centre for parents with disabilities, focusing on all the relevant aspects of pregnancy, childbirth and parenting. A national research study will be commissioned to gain an understanding on issues and to develop strategies to address the needs of parents with disabilities (WWDA, 2008). These proposals may assist in developing future appropriate services for women with disabilities.

## 6.9. Canada

### 6.9.1. Introduction

The provision of maternity care in Canada is the responsibility of the individual provinces, consequently policies and programmes are implemented locally with varying degrees of success. There is no centralised policy regarding care provision and accountability is not consistent across jurisdictions (The Society of Obstetricians and Gynaecologists of Canada, 2003).

### 6.9.2. Legislation relating to people with disabilities

The Canadian Charter of Rights and Freedoms 1982 (Canadian Office for Disability Issues, 2006) is a legislative framework that affords all Canadian citizens fundamental rights and freedoms. In relation to equality rights, the Charter recognises that 'every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and in particular, without discrimination based on ...sex, mental or physical disability' (Canadian Office for Disability Issues, 2006:section 15(1)). Chapter H-6 of the Charter clearly indicates the actions that constitute discriminatory practices, and discrimination on the basis of disability is prohibited. The Charter indicates that to deny access to any service or facility to any individual and to differentiate on the grounds of disability, constitutes discriminatory practice. However, adopting a special programme, designed to ensure inclusiveness and to prevent or reduce disadvantage for people with disabilities may not be considered discriminatory.

The Canadian Human Rights Act, which was enacted in 1985 (Canadian Department of Justice, 1985), outlaws discrimination and promotes inclusion and accommodation of all in society. Such inclusion is not explicitly related to equity of access to maternity and early motherhood services but is focused more on employment and accessibility.

### **6.9.3. Policies relating to women with all disabilities**

#### **6.9.3.1. National guideline documents on disability**

Disability policy is informed by the provisions of the Canadian Charter of Rights and Freedoms 1982 (Canadian Office for Disability Issues, 2006). Jongbloed (2003) suggests that there is no strategic approach to the development of policy in Canada, rather programmes and policies develop incrementally in response to separate issues. In addition, disability is intrinsically linked with the welfare-state policies, which are also fragmented and, as a state, Canada has not explored the concept of disability or the issues surrounding the concept in any great depth (Jongbloed, 2003).

‘In Unison’ was the first policy document on generic disability (Government of Canada, 1997) and was heralded as the blueprint that was to be the springboard for subsequent disability policies. This document was the first substantive policy to advocate and promote the integration of people with disabilities into mainstream life in Canada. Similar to policies in other countries, the policy and vision therein was grounded in the principles of equality, inclusion and independence. The focus of the policy was disability supports, income and employment, rather than on health. Accessibility is discussed within the concept of full citizenship, directing that future policies should promote access to programmes and services for all, including people with all disabilities.

‘Advancing the Inclusion of People with Disabilities’ (Human Resources and Social Development Canada, 2006) is the most recent national report, which charts the government’s progress on generic disability issues. The report identified that 30 federal departments or agencies have implemented 50 programmes and initiatives. None of the federal departments or agencies have implemented specific policies or programmes pertaining to pregnancy, childbirth or motherhood for women with disabilities.

### **6.9.3.2. National guideline documents on women's health or maternity care**

One programme, the Canadian Prenatal Nutrition Program (Public Health Agency of Canada, 2008a) introduced first in 1994, has increased the accessibility of services for pregnant women at risk and has assisted communities to develop or enhance programmes for at-risk pregnant women. The launch of the Canadian Women's Health Strategy, in 1999 (Government of Canada, 1999b), espoused the Canadian government's commitment to ensuring that all programmes and policies developed in government departments would incorporate gender-based analysis. Reference is made in the strategy to women with disabilities, but only in relation to their under-representation and exclusion as stakeholders in policy formation and decision making. The strategy acknowledges how women with disabilities are disadvantaged and doubly discriminated against on the basis of gender and disability, but the specific needs of these women are not set out. In addition, maternity care, reproductive rights and sexual health issues are not discussed in any way, either directly or indirectly (Government of Canada, 1999b).

National guidelines for 'Family centred maternity and newborn care', first published in 1968 and now in their fourth edition (Public Health Agency of Canada, 2008b), were developed following a process of collaboration involving 70 professionals and consumers of the health services. Initially a core group was set up to plan the development and formulation of the guidelines; thereafter, 13 multidisciplinary working groups were established to develop the content and writing of the guidelines. The guidelines are not concerned with clinical practice; rather they are directed towards policy makers, healthcare providers, managers, administrators and parents. It is intended that they would assist in the planning, implementing and evaluating of programmes and services for women and newborn babies. Women with disabilities are not mentioned in the guidelines, nor in the chapter that discusses facilities and equipment.

The British Columbia Centre of Excellence for Women's Health, in consultation with other government departments and service users, developed a provincial Women's Health Strategy (British Columbia Centre of Excellence for Women's Health, 2004).

The overarching aim of the strategy reflects the aim of the national strategy (Government of Canada, 1999b), to improve the health of all girls and women throughout British Columbia. Similar to other documents of this type, women with disabilities are not specifically mentioned; however, success in achieving women-centred care, a concept identified in the strategy, will overcome some of the barriers that women with disabilities may encounter when accessing and availing of health services. Unlike the national Women's Health Strategy (Government of Canada, 1999b) this provincial strategy does discuss access to maternity care. It recognises the challenges that the province is experiencing in relation to access and discusses initiatives currently in place to ensure access to care. However, the strategy does not refer specifically to women with disabilities and their maternity care needs.

#### **6.9.3.3. Guidelines and standards from professional bodies**

The Society of Obstetricians and Gynaecologists of Canada (SOGC) have committed to promoting and adhering to the provisions outlined in an international joint policy statement dated December 2004, pertaining to the professional and ethical responsibilities when providing reproductive healthcare to all women (Federation of International Gynaecologists and Obstetricians (FIGO), 2004). Enshrined in this policy is the commitment to adhere to the principle of non discrimination and to be respectful of women's autonomy. In addition, the SOGC are committed to removing and reducing the many barriers that inhibit inclusiveness and participation of disadvantaged and minority groups (SOGC, 2003). Women with disabilities are not specifically mentioned, although they do fall within the remit of disadvantaged groups.

### **6.9.4. Policies relating to women with mental health difficulties**

#### **6.9.4.1. National guideline documents**

The Public Health Agency of Canada's National Guidelines on Family Centred and Newborn Care (Public Health Agency of Canada, 2008b) recommends the introduction of psychosocial risk assessments for every woman during prenatal care. The guidelines specify the use of the antenatal Psychosocial Health Assessment

(ALPHA). The ALPHA guide assesses support networks; stress and anxiety; support for fathers, and relationships between couples. Questions are also asked about sexuality, violence and substance abuse. Women are also asked about recent stressful life events and how they feel about the pregnancy. The woman is asked whether there is a history of psychiatric/emotional problems and is assessed for depression. The follow up plan includes supportive counselling, additional pre and postnatal appointments, extra well-baby visits and if necessary the involvement of social services, psychologists, psychiatrists and solicitors (Public Health Agency of Canada, 2008b).

In 2003, the Women's Hospital and Health Centre produced guidelines outlining best practice for the care of women with mental illness, their partners, and children during the perinatal period. This comprehensive set of guidelines uses a bio-psycho-social-spiritual framework for the early identification, assessment, treatment and follow-up of women with mental illness during the perinatal period. Emphasis is placed on the psychosocial context, careful discharge plans and community follow up, and an integrated case management process is recommended (British Columbia Ministry of Health, 2003).

#### **6.9.4.2. Guidelines and standards from professional bodies**

The Registered Nurses Association of Ontario produced a comprehensive set of practice recommendations in 2005 (National Guideline Clearinghouse, 2005). Major recommendations include the initiation of preventative measures in the early postnatal period; confirming postnatal symptoms with the Edinburgh Postnatal Depression Scale and immediate assessment of self-harm if the mother scores positive on item number 10 of the Edinburgh Postnatal Depression Scale. Recommendations include weekly contact and ongoing assessment for depressed women, service developments such as the establishment of local care pathways, policy guidelines and the education of health professionals.

#### **6.9.5. Policies relating to women with intellectual disabilities**

Canadian social policy recognises the health disparities that face persons with intellectual disabilities (Ouellette-Kuntz et al, 2005), one of which relates to inaccessible and inadequate healthcare services (Beiser and Stewart, 2005). None of the Canadian maternity documents located made any reference to women with intellectual disabilities. These documents included the *Family-Centred Maternity and Newborn Care: National Guidelines* (Public Health Agency of Canada, 2008b) and the *Canadian Prenatal Nutrition Program* (Public Health Agency of Canada, 2008a). This latter document identifies the need to 'reach pregnant women who are least likely to seek timely prenatal support' (Public Health Agency of Canada, 2008a:6), women with intellectual disability are not one of the groups identified. Ouellette-Kuntz et al (2005) concur that women with disabilities in Canada are not receiving the health services that they need and note the fact that no policy document exists in Canada to address the needs of people with intellectual disabilities.

#### **6.9.6. Recent State reforms**

The Accessibility for Ontarians with Disabilities Act (Government of Ontario, 2005) was enacted in June 2005. The Act confers a statutory obligation on the Ontario government to develop accessibility standards that would identify, erase and prevent barriers to access for people with disabilities. Standards will be devised by standard development committees comprised of all key stakeholders including people with disabilities, and the objective to be achieved is that Ontario will be accessible for people with disabilities by 2025. In January 2008 the first standard, accessible customer service, was enacted into federal law and public sector organisations are now required to comply with the regulation by January 1<sup>st</sup> 2010, and private sector organisations by 2012. (Government of Ontario, 2005).



## **6.10. United States of America (USA)**

### **6.10.1. Introduction**

Although 40 to 50 million people in the USA have a disability (Field and Jette, 2007), no policies relating to the provision of care for women with disabilities during pregnancy, childbirth and early motherhood were found. Only one instrument, the American with Disabilities Act (United States Department of Justice, 1990 (amended in 2008)), identifies the healthcare providers' duty of care in relation to specific elements such as accessible physical environment, communication and information.

### **6.10.2. Legislation relating to people with disabilities**

The American with Disabilities Act (ADA) (United States Department of Justice, 1990) is the cornerstone of disability policy in the USA. The Act, an amendment to which was signed into law on 25<sup>th</sup> September 2008 and becomes effective on 1<sup>st</sup> January 2009 (United States Department of Justice, 2008), is an instrument grounded in the philosophy that all persons have a right to equal access to public services and goods, including people with disabilities. The Act requires that people with disabilities have the right to equal access to healthcare provided by both public and private bodies. Title II of the Act applies to all activities of the state and local government regardless of size or amount of federal funding received (United States Department of Justice, 2005). The Architectural Barriers Act (United States Department of Justice, 1968) provides the legislative framework that sets the architectural standards that state and local governments are required to follow for the construction or renovation of new or existing buildings.

In 2008, the Department of Human Services of the General Assembly of Illinois issued the Perinatal Mental Health Disorders Prevention and Treatment Act. The Act addresses perinatal mental health disorders stating that they are commonly referred to as post-partum depression. The purpose of the Act is to provide information and early intervention, which may help women avoid pharmacological treatment (Illinois Department of Human Services, 2008).

### **6.10.3. Policies relating to women with physical and sensory disabilities**

The American with Disabilities Act obliges public bodies to ensure that all healthcare programmes are accessible to people with disabilities. In addition, public bodies must make 'reasonable modification' in all its policies, practices and procedures to avoid discriminating against people with disabilities. However, if the public body can prove that a modification would alter the nature of services or programmes offered it is not obliged to adhere to this provision (United States Department of Justice, 1990).

During the construction or renovation of new or existing buildings, state and local governments are required to follow and adhere to specific architectural standards governed by the Architectural Barriers Act (United States Department of Justice, 1968). In addition to physical accessibility, public bodies are required under the provision of Title II of ADA to ensure appropriate auxiliary aids and services if required to facilitate effective communication with people with a disability. Again, if the public body can demonstrate that the provision of such auxiliary aids will fundamentally alter the nature of services provided, then compliance with this obligation is redundant. Complaints in respect of Title II can be lodged with the Department of Justice within 180 days of the date of discrimination.

The Department of Justice is responsible for monitoring compliance with the Act and, in 2000, a tenth anniversary status report was released (United States Department of Justice, 2000). The report provides examples of where the Department has enacted procedures to ensure compliance with the provisions set out in the ADA. One case pertains to the provision of interpreters for antenatal parent education classes. The complainant was a deaf woman planning to attend antenatal parent education classes. The person requested the presence of an interpreter for the duration of the class but this request was denied by the medical centre. A complaint was subsequently filed with the Department of Justice and a process of mediation ensued. By means of a resolution, the medical centre agreed to institute a policy ensuring that people with disabilities would in the future receive auxiliary aids and services to facilitate effective communication, including sign language interpreters.

Disability and awareness training would be undertaken by all employees in the centre and the complainant was awarded some monetary compensation.

One pregnancy-specific programme, the Prenatal Care Assistance Program (New York State Department of Health Office of Medicaid Management, 2007) was reviewed. This programme provides outreach co-ordinated services and ongoing assessment and screening of maternal and fetal health during pregnancy, and health and parent education classes are provided for all women. The programme is targeted at low income families and there is no reference to women with disabilities (New York State Department of Health Office of Medicaid Management, 2007).

#### **6.10.4. Policies relating to women with mental health difficulties**

As a result of the recent enactment of the Perinatal Mental Health Disorders Prevention and Treatment Act (Illinois Department of Human Services, 2008), maternity hospitals must provide complete information about perinatal disorders to mothers after the baby is born and before discharge. During pre-natal visits health professionals must provide education to women and, if possible, to their families about perinatal mental health disorders. Each woman is to be invited to complete a questionnaire during the pre-natal period, which fulfils the criteria drawn up by the American College of Obstetricians and Gynaecologists, and a mental health assessment must be repeated when there is a reasonable risk that the mother is suffering from a mental disorder. During postnatal visits women are invited to complete a questionnaire and a follow up questionnaire, which should be administered before the baby's first birthday. Unless the mother presents a serious risk to herself or others, maternity hospitals do not have to administer questionnaires or screening but they have to provide information to mothers and, if possible, to their families. Those involved in the introduction of the legislation envisage that implementation will have a positive effect on the identification, prevention and treatment of perinatal mental health disorders.

#### 6.10.5. Policies relating to women with intellectual disabilities

As with many other countries, service provision for persons with intellectual disabilities in the USA were initially provided within a framework of eugenics with institutionalisation and sterilisation (Block, 2002; Parish, 2002; Race, 2007). This was followed by a movement towards normalisation rooted in the civil rights movements of the 1960s. In keeping with the new focus on civil rights, the Americans with Disabilities Act of 1990 (United States Department of Justice, 1990) sets out to address 'equal opportunities for individuals with disabilities' within the context of the 'Public Health and Welfare' (Title 42). However, it focuses on employment rights and accessibility, stating little of relevance to the maternity needs of women with intellectual disabilities.

The principal United States policy document on intellectual disabilities entitled *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (United States Department of Health and Human Services, 2002) was published in 2002. Centred on 6 health-oriented goals, this report hones in on the importance of health promotion for people with intellectual disabilities. Of relevance to this discussion, it identifies the need for education in safe sex and family planning as well as protection from rape and sexual abuse. Whilst no specific mention is made of maternity care for women with intellectual disabilities, the report does stress the importance of individualised services for such persons with quality outcomes related to health maintenance and 'life goals across the individual's lifespan' (United States Department of Health and Human Services, 2002:10).

Prenatal Care Assistance Programs, which are suggested to 'deliver quality, comprehensive prenatal care services to eligible low-income uninsured and underinsured women' (New York State Department of Health Office of Medicaid Management, 2007:3), are in place. This scheme is specifically available for those who are in receipt of Supplemental Security Income (SSI) (New York State Department of Health Office of Medicaid Management, 2008). The U.S. Social Security Administration website advises that people with disabilities are eligible for SSI (United States Social Security Administration, 2008), which might indicate that some women with intellectual disabilities would be eligible for a state-funded

individualised prenatal care plan (New York State Department of Health Office of Medicaid Management, 2003).

## 6.11. Summary

### 6.11.1. Introduction

In this chapter the legislation, guideline and relevant policy documents of 9 countries were reviewed: the United Kingdom (UK), the Netherlands, Sweden, Norway, Denmark, New Zealand (NZ), Australia, Canada and the United States of America (USA). All countries have legislation in place to protect the rights of people with disabilities, from the Canadian Charter of Rights and Freedoms established in 1982 (Canadian Office for Disability Issues, 2006) to the Prohibition of Discrimination Act published more recently in Sweden (Government of Sweden, 2003). The majority of countries enacted their disability legislation in the 1990s and base their disability strategies and policies on the United Nations Standard Rules on Equalisation of Opportunities for People with Disabilities (UN, 1993).

### 6.11.2. Disability strategies

The UK appeared to have the most developed strategy for women with disabilities and for their maternity care, with a requirement for each primary care trust to publish a Disability Equality Scheme that is reviewed at 3-year intervals. Published examples of good practice include 2 hospitals that have appointed a disability advisor to support both patients attending the services and all staff working in the organisation, and to act as an advocate as required.

In New Zealand, objective 14 of the disability strategy (New Zealand Ministry of Health, 2001a) refers to women and it focuses only on improving the opportunities for women with disabilities to access appropriate disability services (not maternity services) that will enhance their quality of life. Similarly, the Commonwealth Disability Strategy introduced in 1994 (Australian Government, 1994), revised in 2000 (Australian Government, 2000) and evaluated in 2006 (Erebus International, 2006)

did not focus very strongly on women. The evaluation did, however, show that Government departments in Australia have a greater awareness of the need to ensure that their policies and practices are inclusive of people with disabilities and that there is better access to buildings, greater availability of adaptive technology and increased accessibility to information. None of the other 6 countries reviewed had a formal disability strategy, although some had developed disability policies and plans.

### **6.11.3. Guidelines from professional bodies**

The professional bodies in only 4 of the countries produced guidelines relating to the care of women with disabilities. In the UK, the Royal College of Obstetricians and Gynaecologists in collaboration with the Royal College of Midwives, the Royal College of Anaesthetists and the Royal College of Paediatrics and Child Health, developed an agreed set of national standards for maternity care (RCOG, 2008), which is the only document from all countries that considers women with disabilities in the context of reproductive care. The Royal College of Nursing has also published guidelines to assist midwives and nurses in addressing the needs of a woman with a physical or sensory disability during pregnancy, childbirth and motherhood (RCN, 2007). The professional bodies do not provide much detail in relation to maternity care of women with intellectual disabilities, with the Royal College of Midwives and the Royal College of Nursing both acknowledging that they have specific maternity care needs (RCM, 2000; RCN, 2007), but offering limited insight into what those needs might be.

The Royal Australian and New Zealand College of Psychiatrists produced a perinatal mental health plan stating that anti-depressant treatment should continue throughout the pregnancy (Royal Australian and New Zealand College of Psychiatrists, 2005). Following delivery, the plan recommends that the mother should be cared for in a single room in the postnatal ward for as long as possible, so that she can be given enhanced support in establishing feeding. A statement by The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (2007) asserts that all maternity staff are responsible for identifying symptoms of depression during pregnancy that may be a risk factor in the development of postnatal depression.

The Society of Obstetricians and Gynaecologists of Canada (SOGC) have committed to promoting and adhering to professional and ethical responsibilities when providing reproductive healthcare to all women (FIGO, 2004). Enshrined in this policy is the commitment to adhere to the principle of non discrimination, and to remove and reduce the many barriers that inhibit participation of disadvantaged and minority groups (SOGC, 2003), which, arguably, could include women with disabilities. The Registered Nurses Association of Ontario produced a comprehensive set of practice recommendations for mental health care, including the initiation of preventative measures in the early postnatal period, confirming symptoms with the Edinburgh Postnatal Depression Scale and immediate assessment of self-harm (National Guidelines Clearing House, 2005).

#### **6.11.4. Guideline and policy documents**

Again, in the UK, a guidance document was published that establishes standards for the promotion of health and well-being of mothers (UK Department of Health, 2004a). Standard 11 of this document focuses on the development of an accessible, supportive quality maternity service planned around women's individual needs. Recognising that women with disabilities often feel excluded and disconnected from the services, actions to ensure more inclusiveness are proposed. Specific reference is made to women with physical and intellectual disabilities, and service providers are advised to ensure that local maternity services are inclusive and that attention is given to women's communication, equipment and support needs. In contrast, a more recent document designed to improve choice, access and care for all women requiring maternity services, makes no specific recommendations for women with disability (UK Department of Health, 2007).

With regard to mental health services in the perinatal period, the National Institute for Health and Clinical Excellence in the UK has developed organisation of care guidelines recommending clinical networks, the use of specialist mother and baby units, and provision of expert advice about the risks and benefits of psychotropic medication during pregnancy and breastfeeding (NICE, 2007). Further guidelines

from the Scottish Intercollegiate Network also suggest that high risk mothers may benefit from postnatal visits, psychological therapy and/or antenatal education, and that women with a high risk of puerperal psychoses should be reviewed by psychiatric specialists (SIGN, 2002).

No specific reference to the maternity needs of women with intellectual disabilities was found in the key strategy and review documents from the 4 regions of the UK (Scottish Executive, 2000b; UK Department of Health, 2001; Welsh Assembly, 2001; UK Department of Health, Social Service and Public Safety, 2004; 2007). Two policy documents, however, do reflect a view that maternity and intellectual disability services should work in partnership, with an emphasis on multidisciplinary community services.

In New Zealand, the Action Plan for New Zealand Women (New Zealand Ministry of Women's Affairs, 2004) set out a number of measures to improve the quality of life of New Zealand women, including the improvement of women's mental health and sexual and reproductive health. In Australia, a number of policies address generalist healthcare, but without mentioning women with disabilities specifically. The Victorian Women's Health and Wellbeing Strategy 2002-2006 (Victorian Government Department of Human Services, 2002b) does refer to women with disabilities, acknowledges that they can be one of the most disadvantaged groups in society, and identifies the importance of providing accessible health information and services for this population. The Australian Capital Territory Women's Plan (ACT Office for Women, 2004) does refer to women with physical disabilities in the context of accessible built environment but this is the only reference to this cohort. 'Women with Disabilities Australia' (WWDA) recently produced a policy paper highlighting principal human rights for women with disabilities including 'motherhood, sexuality and reproductive rights' (WWDA, 2008:12).

The Canadian Women's Health Strategy (Government of Canada, 1999) acknowledges how women with disabilities are disadvantaged and doubly discriminated against on the basis of gender and disability, but does not address the specific needs of these women. In the area of mental health, Canada's National



Guidelines on Family Centred and Newborn Care (Public Health Agency of Canada, 2008b) recommends the introduction of psychosocial risk assessments for every woman during prenatal care. None of the Canadian maternity documents located made any reference to women with intellectual disabilities.

Although there is comprehensive disability legislation in the United States of America and a number of strategy and policy documents on disability, there is no national strategy addressing specifically the needs of women with disabilities during pregnancy, childbirth and early motherhood. One policy document on intellectual disabilities identifies the need for education in safe sex and family planning as well as protection of people from rape and sexual abuse, and stresses the importance of individualised services.

The remaining 4 countries had very little in the way of published policy in English in this area. Disability policy in the Netherlands is in the early stages of development. In Norway, the National Health Plan 2007-2010 (Norwegian Ministry of Health and Care Services, 2007a) emphasises the importance of providing accessible health services for people with disabilities, but there is no detail relating to maternity care. The Danish Government does not have an overall policy on care of people with disabilities, but one paper does recommend early interventions for postpartum depression, and emphasises the need to protect the mother child-relationship (Government of Denmark, 2002). Sweden's disability policy (Ministry of Health and Social Affairs, 2001) does not consider health or maternity care in any detail.

#### **6.11.5. Conclusion**

All countries reviewed possessed legislation relating to the care of people with disabilities, and the 4 English-speaking countries discussed (UK, New Zealand, Australia and Canada) also had guidance from their professional bodies on this area of care. Three of those 4 countries (UK, New Zealand and Australia) had a country-wide disability strategy, and 3 countries (Canada, Australia and New Zealand) had a national women's strategy but only 2 of the strategies (from Australia and New Zealand) referred to women with disabilities. The UK, in particular, has a number of

well developed policies and guidelines in this area. In general, women with intellectual disabilities were the least recognised group included in the available plans in all countries.

Overall, Ireland compares reasonably well with the other countries reviewed. The Irish Government has recently enacted a Disability Act (Government of Ireland, 2005a), which forms the core element of the National Disability Strategy (Government of Ireland, 2004b). There is, however, little or no guidance from professional bodies on the care of people with disabilities in the areas of pregnancy, childbirth and early motherhood in the country. With the exception of the UK, Ireland appears to have better-developed plans than all other European countries and many of the states in the USA and Canada. However, there is no room for complacency, as the Irish policies are not specific to the care of women with disabilities during pregnancy, childbirth and early motherhood, nor are they implemented universally or completely. In the final chapter of this review, a summary overview is provided. The main policy deficiencies are highlighted and recommendations are made for all key stakeholders.

## **Chapter Seven: Summary, conclusion and recommendations**

### **7.1. Summary overview**

#### **7.1.1. Disability legislation**

This comprehensive review of national and international policies has revealed that, although legislation protecting the rights of people with disabilities exists in Ireland and the other 9 countries studied, the implementation of that legislation is not yet fully developed. The stimulus for all international legislation and policies was the United Nations Universal Declaration of Human Rights in 1948 (UN, 1948), leading to the development of the United Nations Convention on the Rights of Persons with Disabilities in 2006 (UN, 2006). All states that have signed the convention are obliged to submit periodic reports of their compliance, so it can be expected that further policies will be developed in the near future.

#### **7.1.2. International calls to improve the care for people with disabilities**

The Council of Europe's Disability Action Plan (2006-2015) (Council of Europe, 2006) provides a useful framework to guide policy makers in member states when designing, implementing and evaluating disability policies and strategies. The plan advocates the application of the principle of Universal Design to create an accessible barrier-free environment for people with disabilities. Provisions of the plan set out how member states should ensure that all people with disabilities have equal access to all health services including antenatal, gynaecology and family planning services. It indicates the importance of disability awareness and training as a mechanism to meeting the specific needs of people with disabilities. The integration of a mental health component as a universal aspect of maternal health policies, plans and activities is recommended by the WHO (2001), so that Millennium Development Goal 5, which is to improve maternal mental health, can be achieved.

### **7.1.3. Developments in Ireland to improve the care of people with disabilities**

In Ireland, considerable reform in the structure and organisation of the health service has taken place with the establishment of the Health Service Executive, the adoption of a more strategic, policy development position for the Department of Health and Children, and the establishment of the Health Information and Quality Authority. The Health Service Executive was established in 2005 following the Health Act 2004 (Government of Ireland, 2004e), and is responsible for the provision of health and personal social services in Ireland. Its transformation programme 2007-2010 (HSE, 2006) includes the transformation of maternity services as one of its major actions; however, there are no specific policies documented that cater for women with disabilities during pregnancy, childbirth and early motherhood. In 1996, the Irish government established the Commission on the Status of People with Disabilities, who acknowledged that women with disabilities were discriminated against, and were often perceived as asexual. Recommendations from the Commission led to the establishment of the National Disability Authority in 2000 under the aegis of the Department of Justice, Equality and Law Reform. Following this, the Disability Act (Government of Ireland, 2005a) was signed into law in July 2005. From this, the National Disability Strategy (Government of Ireland, 2004b) was developed, which requires all public bodies to ensure that services provided by the organisation are accessible, appropriate and equitable for people with a disability.

Although no national policies relate specifically to women with disabilities who wish to access maternity services, some recommendations contained within other health policies and strategies are applicable. In addition, recent legislation (Government of Ireland, 2005a; 2007) may provide for better care for women with disabilities in the future. Under the terms of the Disability Act, the Department of Health and Children is required to publish a sectoral plan to implement the requirements of the Act. These plans are subject to annual review, which should lead to improved facilities being made available to all persons with disabilities.

No guidance is provided by any of the 4 relevant professional and academic bodies in the country (An Bord Altranais, the Medical Council, the Irish College of General Practitioners and the Royal College of Physicians of Ireland) on the care of women

with disabilities when accessing services during pregnancy, childbirth and early motherhood. A survey of the 19 publicly-funded maternity units in the country found that only one of them had a written policy governing practice and procedure in service provision for women with disabilities when accessing their services during pregnancy, childbirth and early motherhood. A clear finding that emerged from this study was that services tend to be more reactive than proactive and the provision of services is curtailed by many barriers including financial, infrastructural and human resources.

Despite the existence of a number of strategies and policies, no specific policy governs procedure and practice in service provision for women with any disability when accessing publicly-funded healthcare during pregnancy, childbirth and early motherhood in Ireland. At a national level, Parts 2 and 3 of the Disability Act (Government of Ireland, 2005a) confers a statutory obligation on service providers to determine the individual needs of women, to ensure access to buildings and to provide information in an accessible and appropriate format, not all of which appeared to be happening in all maternity hospitals/units.

#### **7.1.4. A comparison of Irish and international policies relating to the care of women with disabilities during pregnancy, childbirth and early motherhood**

To provide a comparison with the Irish situation, the legislation, guidelines and relevant policy documents of 9 countries were reviewed. All countries have legislation in place to protect the rights of people with disabilities, usually developed in the 1990s and based on the United Nations Standard Rules on Equalisation of Opportunities for People with Disabilities (UN, 1993). Overall, the UK had the most developed disability strategy on maternity care; New Zealand and Australia had disability strategies but they did not focus very strongly on women. None of the other 6 countries reviewed had a formal disability strategy, although some had developed disability policies and plans.

The professional bodies in the UK had developed an agreed set of national standards for maternity care (RCOG, 2008), which is the only document from all

countries reviewed that considers women with disabilities in the context of reproductive care. Some professional bodies in Australia, New Zealand and Canada have produced brief guidelines on the care of women with certain disabilities, such as mental health difficulties.

In terms of policy and guideline documents, again the UK has a more detailed range of policies and they are of a higher quality than those of other countries. Specific reference is made in some (Scottish Executive, 2001; Department of Health, 2004a; 2004b) to women with physical and intellectual disabilities, and service providers are advised to ensure that local maternity services are inclusive and that attention is given to women's communication, equipment and support needs.

In New Zealand and Australia, policy documents promote the improvement of women's mental, sexual and reproductive health and emphasise the importance of providing accessible health information and services for women with disabilities. Canadian policies acknowledge how women with disabilities are disadvantaged and doubly discriminated against on the basis of gender and disability, but do not address the specific needs of these women.

Although there is comprehensive disability legislation in the United States of America and a number of strategy and policy documents on disability, there is no national strategy addressing specifically the needs of women with disabilities during pregnancy, childbirth and early motherhood. It has not been possible to locate much published material in the Netherlands, Norway, Denmark and Sweden on disability policy and no reference is made to the maternity care needs of women with any disabilities.

#### **7.1.5. Discussion**

Some countries within this review have a designated disability policy that addresses the broader issue of accessibility, but in most cases access to health services and, more specifically, reproductive and sexual health services are not discussed. In particular, for persons with intellectual disabilities or mental health issues, some

governments have advanced policy in the areas of employment, accessibility and security of income (Ouellette-Kuntz et al, 2005) whereas areas such as sexuality, reproductive or maternal rights for women with intellectual disabilities are more complex, and have not received the same level of attention (Center for Reproductive Rights, 2002). In Ireland, this is reflected in legislation such as the Criminal Law (Sexual Offences) Act 1993 (Government of Ireland, 1993), which essentially criminalises sexual activity for persons with intellectual disability (except with a spouse) under the view that such persons are unable to consent. The NDA put forward 2 submissions on the Mental Capacity Scheme of Bill in early 2009 (NDA 2009a, 2009b) suggesting changes to this legislation and, in particular, recommending that sexual relationships between adults who have capacity, but are vulnerable, should be decriminalised (NDA 2009b). It was further recommended that abuse, exploitation or sexual relationships with people with intellectual disability by staff caring for them should become an explicit offence, and that sex and relationships education programmes should be instituted for people with intellectual disability (NDA 2009b).

Policy recommendations for service initiatives in the area of perinatal mental health are fragmented and, as yet, comprehensive policies in the countries reviewed are in a nascent stage of development. The literature reflects the current state of psychiatry in that psychosocial perspectives are only gradually starting to undermine traditional biomedical perspectives in which professional control and treatment hold sway. Although there are some examples of innovation, a gap between service recommendations and service provision emerges from the literature. There is also a dearth of evidence on the best interventions on which to base service development. Perhaps most importantly, the views of women are missing from service recommendations and from evaluations of existing service provision.

The current literature indicates that perinatal mental health policy largely focuses on maternal depression, and the term 'postnatal depression' tends to be used as an all embracing category for perinatal mental health difficulties; this aligns with the biomedical approach that pervades psychiatric and general health services. While the term 'depression' may be a means of reducing the stigma associated with serious

mental illness (Brockington, 2004), the widespread use of this term in connection with childbirth can have serious consequences in that other perinatal mental health disorders are not considered.

Evidence from various international Government Health Department websites indicates that an effort is being made to provide women with information about mental health difficulties associated with pregnancy, such as *Beyondblue: the national depression initiative* (Beyondblue, 2007) in Australia. A variety of information mainly about postnatal depression is offered, but this may not reach women lacking access to computers. Psychological distress triggered by psychosocial factors such as deprivation, domestic violence and substance abuse do not receive a high profile on these websites and the impression given is that postnatal depression is the acceptable face of mental health difficulties associated with motherhood.

#### **7.1.6. Conclusion**

The lack of policies governing the provision of care for women with disabilities who wish to access services during pregnancy, childbirth and early motherhood in Ireland is comparable to the international situation. With the exception of one country, the United Kingdom, the majority of the countries reviewed have no specific, well-developed policy. Disability was an obvious omission from many of the gender-specific policies and, where it was discussed, it tended to be within the context of employment and education. Reproductive healthcare and women with disabilities remain disconnected, which is reflective of society's misconception that such women are asexual. The review reiterated the contention that women with disabilities are less 'visible' than other citizens and, despite many policies advocating principles of equity, participation and inclusiveness the care provided for these women remains sub-optimal.



## 7.2. Main policy deficiencies

### 7.2.1. At national level

The Irish Disability Act (Government of Ireland, 2005a) and resulting Disability Strategy (Government of Ireland, 2004b) are well-developed documents; however, the Disability Strategy does not include detailed information concerning the care required by women with disabilities who wish to access the maternity services. In addition, the Act and Strategy are both recent innovations and it remains to be seen how well they will be implemented. Strict enforcement of the legislation and close monitoring of the implementation of the Strategy is necessary to ensure high quality care for women with disabilities in the future. In particular, the Sectoral Plans need to include more detailed information concerning service provision for women with all disabilities when accessing maternity services in pregnancy, childbirth and early motherhood.

### 7.2.2. At Health Service Executive level

Detailed national policies, guidelines and standards on maternity services for women with disabilities are lacking and need to be proactively developed, using the UK experience as a template. Resources should be allocated to upgrade physical facilities in maternity units across the country and to provide education and training for staff. Innovations in practice, similar to those introduced in the UK, need to be supported.

### 7.2.3. At professional body level

There is lack of guidance provided by the professional bodies on the care of women with disabilities during pregnancy, childbirth and early motherhood. An urgent need exists for the professional bodies, in collaboration if possible, to issue a guideline to assist health professionals in planning the care of women with disabilities during pregnancy, childbirth and early motherhood. Guidance on the necessity for information on the maternity care needs of women with disabilities to be included in

relevant health professional undergraduate and postgraduate programmes is also required.

#### **7.2.4. At individual maternity hospital/unit level**

A few examples of good practice at individual clinician or unit level were apparent during the national survey, but the almost total lack of unit policies on the care of women with disabilities needs to be addressed. In particular, access audits were not universally conducted and information was not always provided in accessible formats. The needs of women with mental health difficulties or intellectual disabilities were the most overlooked.

### **7.3. Recommendations**

#### **7.3.1. For the Department of Health and Children**

It is recommended that:

- Future editions of the Sectoral Plan be amended to include more detailed information concerning service provision for women with disabilities when accessing services in pregnancy, childbirth and early motherhood.

#### **7.3.2. For the Health Service Executive**

It is recommended that:

- Maternity hospitals and domiciliary midwifery services should have the skilled staff, facilities and service practices to enable them to deliver a quality service to women with disabilities during pregnancy, childbirth and early motherhood. This will require appropriate training for the relevant staff, clinical and non-clinical, in the care of women with disabilities.
- National policies, guidelines and standards be developed, encapsulating core provisions that will impact positively on procedure and practice in

service provision for women with disabilities accessing health services in Ireland during pregnancy, childbirth and early motherhood;

Appendix 6 sets out an example of a 'best practice' guideline, which evolved from the policy review process and is a compilation of a number of sources describing service provision for women with disabilities during pregnancy, childbirth and early motherhood in the UK. The content therein is modified from the 3 professional guidance documents (RCM, 2000; RCN, 2007; RCOG, 2008), which are, in turn, informed by clinical guidance documents produced by the National Institute for Health and Clinical Excellence and the Scottish Intercollegiate Guidelines Network. Conclusion of best practice cannot be drawn, mainly because of the lack of policy documents and research in this area.

### **7.3.3. For professional bodies**

It is recommended that:

- A collaborative guideline be issued to guide clinicians in best practice when caring for women with disabilities during pregnancy, childbirth and early motherhood. An example of a 'best practice' guideline is included in Appendix 6. In addition, with regard to developing guidelines for caring for women with mental health difficulties, it is recommended that the perinatal mental health plan in New Zealand be consulted;
- The content of education programmes leading to registration as a health professional be amended to include reference to the maternity care needs of women with disabilities;

### **7.3.4. For maternity hospitals/units**

It is recommended that:

- A written policy be developed to guide practice when caring for women with a physical, sensory or intellectual disability or mental health illness during

- pregnancy, childbirth and early motherhood. An example of such a 'best practice' guideline is included in Appendix 6;
- A review of the physical infrastructure of each unit be undertaken and buildings and facilities upgraded to provide accessible and suitable services for women with disabilities;
  - An existing member of staff be designated as a disability officer in each maternity hospital or unit to oversee developments in relation to the care of women with disabilities and to provide advice and guidance to staff;
  - Education and training be provided for both clinical and non-clinical staff in the care of women with disabilities;
  - Standardised information booklets in appropriate formats, suitable for women with a physical, sensory or intellectual disability or mental health illness, be developed through collaboration with all maternity units and consultation with voluntary and non-voluntary disability organisations;
  - The mental health education provided for both healthcare professionals and women increases the focus on other mental health difficulties, in addition to pre and postnatal depression;
  - In line with the Code of Practice for Accessible Public Services, it should be ensured that information is made available to pregnant women with disabilities in the formats they require;
  - All maternity units review their policies on the acceptance of guide dogs in main hospital areas, and adapt them in line with best practice.

In all of the above, the views of women with disabilities should be sought, and utilised, in the development of policies, guidelines and services.

### **7.3.5. For clinicians**

It is recommended that:

- In the absence of national guidelines, all clinicians become familiar with, and use, the guidelines relating to the maternity care of women with disabilities produced by UK bodies such as the National Institute for Health and Clinical

Excellence (NICE) and the Royal College of Obstetricians and Gynaecologists (RCOG); an example of a 'best practice' guideline is also included in Appendix 6;

- Clinicians be alert to the possible presence of a mental health condition (of which depression is only one possibility).
- Clinicians develop individual care plans addressing specific needs of all women, including women with disabilities.

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## Appendices

### Appendix 1. Relevant departments and organisations contacted when sourcing policies

Country	Organisation	Contact Details
Ireland	HSE	James O'Grady james.ogrady@mailh.hse.ie
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Ireland	TCD Social Policy	Judy O' Shea osheaju@tcd.ie
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Ireland	TCD Social Policy	Eilish Mc Auliffe emcaulif@tcd.ie
Ireland	Health policy analyst	Maeve Ann Wren rencor@indigo.ie.
Ireland	AIMS	Aims info@aimsireland.com
Ireland	An Bord Altranais (ABA)	Librarian library@nursingboard.ie
Ireland	The Medical Council (IMC)	Lisa Molloy info@mcirl.ie
Ireland	Irish College of General Practitioners (ICGP)	Patricia Patton Patricia.Patton@icgp.ie
Ireland	Royal College of Physicians of Ireland	college@rcpi.ie

Ireland	Institute of Obstetricians and Gynaecologist	iog@rcpi.ie
Ireland	Faculty of Paediatrics	paediatrics@rcpi.ie
Norway	Department of Family Affairs and Gender Equality	postmottak@bld.dep.no
Norway	Department of Family Affairs and Gender Equality Director General -Arni Hole	Arni.Hole@bld.dep.no
Australia	Ministry of Health	Patricia Fronek Patricia_Fronek@health.qld.gov.au
Australia	Information Advocate People With Disabilities(WA) Inc	Stuart Jenkinson info@pwdwa.org
Australia	Disability Services Queensland	disabilityinfo@disability.qld.gov.au
Australia	WWDA	Carolyn Frohmader <a href="mailto:Carolyn@wwda.org.au">Carolyn@wwda.org.au</a>
Australia	Women's Council	info@ncwa.org.au
Australia	Spinal Injury Units	
Australia	Academic – social and health policy	Susan Graham susan-graham@ausdoctors.net
Australia	Academic – social and health policy	Ian Cameron ianc@mail.usyd.edu.au
Australia	Academic – social and health policy	Hugh Dickson Hugh.Dickson@sswahs.nsw.gov.au
Australia	Department of disability, housing and community services	DHCS@act.gov.au
Australia	ACT Office for Women	women@act.gov.au
Australia	Office for Children, Youth and Family Support	DHCS@act.gov.au
Australia	Department of families, housing, community services and indigenous affairs	enquiries@fahcsia.gov.au
Australia	Australian Federation of disability organisation Ltd.	office@afdo.org.au
Australia	ACT for Women	women@act.gov.au
Australia	Disability Service – State government of Victoria, Australia, Department of Human Services	Disability.Services@dhs.vic.gov.au
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Australia	Department of Health and Ageing – Ministerial office	lara.giddings@parliament.tas.gov.au
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Australia	Women's Health Goulburn	whealth@whealth.com.au
Australia	North East Women's Health Loddon Mallee	lmwh@lmwh.net
Australia	WIRE Women's Information	wire@wire.org.au
Australia	Women's Health East	health@whe.org.au
Australia	Women's Health West	info@whwest.org.au
Australia	Women's Health Grampians	adminb@whg.org.au
Australia	Women's Health in the North	info@whin.org.au
Australia	Gippsland Women's Health Service	admin@gwhealth.asn.au
Australia	Victorian Women with Disabilities Network	vwdn@whv.org.au
Australia	Royal Women's Hospital	whic@rwh.org.au
Australia	Multicultural Centre for Women's Health	info@mcwh.com.au
Australia	Shine SA- Sexual health information networking and education	info@shinesa.org.au
Australia	Australian College of Midwives	members@midwives.org.au
Australia	Australian College of Midwives	admin@nswmidwives.com.au
Australia	Australian College of Midwives	membersvic@midwives.org.au
Australia	Disability Advisory Council	OFD@dvc.vic.gov.au
Australia	Disability Service Commissioner	dsc@dsc.wa.gov.au
Australia	Office of Public Advocate	opa@publicadvocate.vic.gov.au
Australia	Sexual Health and Family Planning Act	tbavinton@shfpact.org.au
Australia	Sex Life family planning Victoria	fpv@fpv.org.au
Australia	Parenting Research Centre	info@parentingrc.org.au
Australia	Disability and Community Faculty Research Group	fhs.dean@usyd.edu.au
UK	Department of Health – social policy division	SCPI-Enquiries@dh.gsi.gov.uk
UK	Department of Health – sexual health policy division	Sexual-Health-&-HIV@dh.gsi.gov.uk
UK	Department of Health	dhmail@dh.gsi.gov.uk
UK	Commission for Equality and Human Rights	info@equalityhumanrights.com wales@equalityhumanrights.com
UK	Commission for Equality and Human Rights	scotland@equalityhumanrights.com
UK	Healthcare Commission	feedback@healthcarecommission.org.
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UK	Disability Wales	info@disabilitywales.org
UK	Healthcare Inspectorate Wales	hiw@wales.gsi.gov.uk
UK	Welsh Assembly Government	health.enquiries@wales.gsi.gov.uk

UK	Martin Bradley Chief Nursing Officer	nursingandmidwifery@dhsspsni.gov.uk
UK	Royal College of Midwives	www.rcog.org.uk
UK	Royal College of Obstetricians and Gynaecologists	www.rcm.org.uk
UK	Liverpool Women's Hospital	Jackie Rotherham – Disability Advisor
UK	Milton Keynes Hospital	Patricia Fairlamb – Special needs Advisor
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New Zealand	Office of Disability Issues	odi@msd.govt.nz
New Zealand	Ministry of Health	mwa@mwa.govt.nz
New Zealand	Women's Council	contactus@ncwnz.co.nz
New Zealand	Academic – disability and motherhood	debbie.payne@aut.ac.nz
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New Zealand	College of Midwifery	nzcom@nzcom.org.nz
New Zealand	Disabled Persons Assembly	gen@dpa.org.nz
Sweden	Office of Disability Commissioner	info@handisam.se
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Canada	Children's and Women's Health Centre	mcollins@cw.bc.ca
Canada	Women and wellness: health services and women with disabilities	skerr@yorku.ca
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## Appendix 2. The modified Walt and Gilson policy analysis model (1994)

Country	Title	Context/Background to policy development/ social, economic and political	Actors/ Stakeholders involved in developing the policy	Content	Process
		Previous and/or current strategic policy/policies	Government agencies	Core principles	Implementation, monitoring and evaluation of the policy
		Legislation	Civil servants	Goal(s)/objective(s)	Mechanism of implementation, monitoring and evaluation
		Expert reports	Non govt. agencies	Prevailing model of disability	Funding of the policy
		Socio-cultural factors e.g. status of women, cultural values, attitudes, literacy levels	Women with disabilities	Recognition of diversity among women with disability	
		Determinants of health and goal(s) of policy	Others (identify who)	Accessibility to building and building/environment	
				Service provision - <ul style="list-style-type: none"> <li>• Assessment of needs</li> <li>• Models of care</li> <li>• Integrated services</li> <li>• Continuity of care</li> <li>• Personal advocate</li> </ul>	
				Effective modes of communication, provision of information in appropriate formats	
				Equipment and auxiliary aids	
				Referral mechanism(s)	
				Disability awareness and training	
				Discharge planning	
				Complaints mechanism	

(Adapted from Walt and Gilson 1994)



### Appendix 3. The survey questionnaire

(attached as separate file)

#### Appendix 4. List of 19 publicly-funded maternity units in Republic of Ireland

**Cavan** - Cavan General Hospital

**Cork** - Cork University Maternity Hospital

**Dublin**

- Coombe Women's Hospital
- National Maternity Hospital
- Rotunda Hospital

**Donegal** - Letterkenny General Hospital

**Drogheda** - Our Lady of Lourdes Hospital

**Galway**

- University College Hospital Galway
- Portiuncula Hospital

**Kilkenny** - St Luke's General Hospital

**Kerry** - Tralee General Hospital

**Laois** - Portlaoise Hospital

**Limerick** - Limerick Regional Maternity Hospital

**Mayo** - Mayo General Hospital

**Sligo** - Sligo General Hospital

**Tipperary** - St. Joseph's Hospital

**Waterford** - Waterford Regional Hospital

**Westmeath** - Midland Regional Hospital

**Wexford** - Wexford General Hospital

## Appendix 5. Survey response of the 19 publicly-funded maternity units

The most common response in each category is highlighted in bold

Survey Question	Response of publicly-funded maternity units (n=19)	
Does your hospital have a written policy on services available for women with disabilities? (n=19)	Yes 5.3% (n=1)	<b>No 94.7% (n=18)</b>
Is an assessment of special/specific needs conducted for any of the groups? (n=19)	<b>Yes, for women with a physical disability</b>	89.5% (n=17)
	<b>Yes, for women with a mental health problem</b>	89.5% (n=17)
	Yes, for women who have a hearing impairment or are deaf	84.2% (n=16)
	Yes, for women who are visually impaired or blind	84.2% (n=16)
	Yes, for women with an intellectual disability	78.9% (n=15)
	None of the above	10.5% (n=2)
Who conducts the assessment? (n=17)	<b>Midwife 94.1% (n=16)</b>	
	Consultant Obstetrician 64.7% (n=11)	
	Register 41.2% (n=7)	
	Physiotherapist 35.3% (n=6)	
	Social Worker 35.3% (n=6)	
Are procedures in place for women with a disability to make their needs known to clinical staff? (n=19)	<b>Yes, for women with a physical disability</b>	89.5% (n=17)
	<b>Yes, for women who are visually impaired or blind</b>	89.5% (n=17)
	<b>Yes, for women who have a hearing impairment or are deaf</b>	89.5% (n=17)
	<b>Yes, for women with a mental health problem</b>	89.5% (n=17)
	<b>Yes, for women with an intellectual disability</b>	89.5% (n=17)
	None of the above	10.5% (n=2)
Does your organisation conduct a formal review of the accessibility of the services it provides? (n=19)	Yes, for women with a physical disability 31.6% (n=6)	
	Yes, for women who are visually impaired or blind 31.6% (n=6)	
	Yes, for women who have a hearing impairment or are deaf 31.6% (n=6)	
	Yes, for women with a mental health problem 31.6% (n=6)	
	Yes, for women with an intellectual disability 31.6% (n=6)	
	<b>None of the above 68.4% (n=13)</b>	
What experts are involved in the formal review? (n=6)	<b>Internal experts 83.3% (n=5)</b>	<b>External experts 83.3% (n=5)</b>
Are written clinical guidelines readily available to frontline staff involved in assisting women with a disability when accessing and using your services? (n=19)	Yes, for women with a physical disability	0% (n=0)
	Yes, for women who are visually impaired or blind	5.3% (n=1)
	Yes, for women who have a hearing impairment or are deaf	0% (n=0)
	Yes, for women with a mental health problem	0% (n=0)
	Yes, for women with an intellectual disability	0% (n=0)
	<b>No for none of the above</b>	<b>94.7% (n=18)</b>

Has your organisation appointed an Access Officer/Disability Officer/Special Needs Officer? (n=19)	Yes 10.5% (n=2)	No 84.2% (n=16)	Don't Know 5.3% (n=1)
Are guide dogs permitted in the hospital? (n=19)	Yes 73.7% (n=14)	No 5.3% (n=1)	Don't Know 21.1% (n=4)
If Yes to above question, are there any restrictions on where a guide dog may be permitted to go? (n=14)	Yes 62.5% (n=10)	No 18.8% (n=3)	Don't Know (n=1)
Are staff trained in sighted guide techniques and methods of how to familiarise a client with vision impairment with the layout of the ward? (n=19)	Yes 5.3% (n=1)	No 89.5% (n=17)	Not answered 1 maternity unit
Do staff introduce themselves verbally to women who are vision impaired? (n=19)	Yes 89.5% (n=17)	No 5.3% (n=1)	Don't Know 5.3% (n=1)
Do staff inform women who are vision impaired before they have any hands on contact? (n=19)	Yes 89.5% (n=17)	Don't Know 10.5% (n=2)	
<b>Has an access audit been conducted? (n=19)</b>			
	Yes 31.6% (n= 6)	No 68.4% (n=13)	
If answered No to above question are all areas within the hospital accessible to people with physical disabilities? (n=13)	Yes, to people using wheelchairs	85.7% (n=12)	
	Yes, to people using walking aids (crutches, calipers, stick, Zimmer frame)	85.7% (n=12)	
	No	5.3% (n=1)	
Is assistance available to wheelchair users? (n=19)	Yes, someone available to assist at all times	100% (n=19)	
Is written information on accessibility to all relevant areas available to people with physical disabilities? (n=19)	Yes 31.6% (n=6)	No 63.2% (n=12)	Don't Know 5.3% (n=1)
Do all departments have height adjustable beds suitable for women with a physical disability? (n=19)	Yes 89.5% (n=17)	No 10.5% (n=2)	
Is there any special equipment available on the labour ward for women with disabilities? (n=19)	Yes 63.2% (n=12)	No 36.8% (n=7)	
Has the hospital environment been assessed in terms of accessibility for people with vision impairments e.g. good adjustable lighting, good colour contrast, steps and stair edges marked, good clear signage etc? (n=19)	Yes 21.1% (n=4)	No 73.7% (n=14)	Don't Know 5.3% (n=1)
<b>Do you routinely screen all women for a history of? (n=19)</b>			
	<b>Depression</b> 89.5% (n=17)	<b>Postnatal depression</b> 89.5% (n=17)	
	Anxiety 84.2% (n=16)	Psychosis 84.2% (n=16)	
	Bipolar disorder 68.4% (n=13)	Domestic violence 52.6% (n=10)	
	Sexual abuse 47.4% (n=9)	None of the above 10.5% (n=2)	
<b>Are clinical staff provided with specific training and education in any of the following areas?</b>			
	Depression 57.9% (n=11)	Postnatal depression 78.9% (n=15)	
	Anxiety 52.6% (n=10)	Psychosis 31.6% (n=6)	
	Bipolar disorder 21.1% (n=4)	Domestic violence 73.7% (n=14)	
	Sexual abuse 42.1% (n=8)	Physical disability 21.1% (n=4)	
	Sensory disability 26.3% (n=5)	Intellectual disability 10.5% (n=2)	

<b>Do women receive information antenatally on perinatal mental health issues?</b>	<b>Routinely give verbal information to all women</b> 63.2% (n=12)	Selectively give verbal information to women with a history of mental health issues 21.1% (n=4)	Routinely give a perinatal mental health booklet to all women 21.1% (n=4)	Selectively give a perinatal mental health booklet to women with a history of mental health issues 5.3% (n=1)	Never 15.8% (n=3)
<b>Do you routinely screen all women for postnatal depression? (n=19)</b>	Yes 47.4% (n=9)		No 52.6% (n=10)		
<b>Do you routinely screen all women for antenatal depression? (n=19)</b>	Yes 47.4% (n=9)		No 52.6% (n=10)		
<b>For women with mental health problems, is there a specialist multidisciplinary perinatal service available within the hospital? (n=19)</b>	Yes 57.9% (n=11)		No 42.1% (n=8)		
<b>If you answered Yes to above question, please indicate the members of the team (n=11)</b>	<b>Psychiatrist</b>		100% (n=11)		
	Psychologist		36.4% (n=4)		
	Counsellor		45.5% (n=5)		
	Community mental health nurse		45.5% (n=5)		
	Specialist mental health nurse		54.5% (n=6)		
	Social worker		54.5% (n=6)		
	Specialist midwife		18.2% (n=2)		
<b>If you answered No, do you have access to a specialist multidisciplinary team outside your service for advice? (n=8)</b>	Yes 77.8% (n=7)		No 11.1% (n=1)		
	Other		9.1% (n=1)		
<b>Are there provisions made to support women who are visually impaired or blind when accessing and using your services (including antenatal visits, antenatal ward, labour ward, postnatal ward, Special Care Baby Unit, postnatal visits)? (n=19)</b>	Yes 47.4% (n=9)		No 52.6% (n=10)		
<b>If you answered Yes to above question, what provisions are available? (n=9)</b>	Information in large print format		28.6% (n=2)		
	<b>Information in braille</b>		42.9% (n=3)		
	Information in audio format		28.6% (n=2)		
	Information in pictorial format		0% (n=0)		
	Other		n=5		
<b>Is assistance available for women who are visually impaired or blind? (n=19)</b>	Yes, someone available to assist at all times 63.2% (n=12)		Yes, someone available to assist - must be pre-arranged 36.8% (n=7)		
<b>Are there provisions made to support women who have a hearing impairment or are deaf when accessing and using your services (including antenatal visits, antenatal ward, labour ward, postnatal ward, Special Care Baby Unit, postnatal visits)? (n=18)</b>	Yes 66.7% (n=12)		No 33.3% (n=6)		

If you answered Yes to above question, what provisions are available? (n=12)	<b>Sign language interpreters</b>		Text message (e.g. to notify clinic appointments)
	100%		30.8% (n=4)
	E-mail message (e.g. to notify clinic appointments)		Fax (e.g. to notify clinic appointments)
	38.5% (n=5)		15.4% (n=2)
	Plain English format		Minicom
	30.8% (n=4)		0% (n=0)
	Loop System		Other
	15.4% (n=2)		(n=1)
Is assistance available for women who have a hearing impairment or are deaf? (n=19)	<b>Yes, someone available to assist at all times</b>	Yes, someone available to assist - must be pre-arranged	No
	47.4% (n=9)	36.8% (n=7)	13.8% (n=3)
Are there provisions made to support women who have an intellectual disability when accessing and using your services (including antenatal visits, antenatal ward, labour ward, postnatal ward, Special Care Baby Unit, postnatal visits)? (n=19)	Yes	<b>No</b>	
	42.1% (n=8)	57.9% (n=11)	
If Yes to above question what supports are available to these women? (n=8)	Support person to accompany them at all times	42.9% (n=3)	
	<b>Support person responsible for co-ordinating their care while accessing the services</b>	57.1% (n=4)	
	Support person on call	14.3% (n=1)	
	Other support	28.6% (n=2)	
Do you have information available (eg 'Easy to Read format', pictorial) that has been tailored for use by women with an intellectual disability? (n=19)	Yes	<b>No</b>	
	15.8% (n=3)	84.2% (n=16)	
<b>Do clinical staff receive disability awareness and training? (n=19)</b>	Yes 22.2% (n=4)	<b>No 77.8% (n=15)</b>	
<b>Do non-clinical staff receive disability awareness and training? (n=19)</b>	Yes 26.3% (n=5)	<b>No 73.7% (n=14)</b>	
If Yes to above question please tick all non-clinical staff that receive disability awareness and training (n=5)	Portering staff	60.0% (n=3)	
	Administration staff	20.0% (n=1)	
	<b>Maternity Care assistants</b>	100% (n=5)	
For women with a physical and/or sensory disability (visual or hearing impairment), do you have a mechanism for liaison with community services? (n=19)	<b>Yes</b>	No	
	94.7% (n=18)	5.3%(n=1)	
For women with mental health problems, do you have a mechanism for liaison with community mental health services? (n=19)	<b>Yes 100% (n=19)</b>		
For women with an intellectual disability, do you have a mechanism for liaison with community services? (n=19)	<b>Yes</b>	No	
	84.2% (n=16)	15.8%(n=3)	
Do you have advocacy services for women with intellectual disability? (n=19)	Yes, within the service	Yes, external to the service	<b>No</b>
	10.5% (n=2)	10.5% (n=2)	78.9% (n=15)

<b>Do you have advocacy services for women with mental health problems? (n=19)</b> <i>1 unit has access to both internal and external services</i>	Yes, within the service 21.1% (n=4)	Yes, external to the service 15.8% (n=3)	<b>No</b> 68.4% (n=13)	
<b>Is there a designated person that clinical staff can contact if they have queries regarding services required by women with a disability? (n=19)</b>	Yes 26.3% (n=5)	<b>No</b> 57.9% (n=11)	Don't Know 5.3% (n=1)	Not answered 10.5% (n=2)
<b>Do you have access to interpreters/translators, sign language interpreters or Braille translators in any language other than English? (n=19)</b>	<b>Yes, access to interpreters/translators in non-English languages</b>		<b>84.2%</b> (n=16)	
	Yes, access to sign language interpreters in non-English languages		31.6% (n=6)	
	Yes, access to Braille translators in non-English languages		10.5% (n=2)	
	No		15.8% (n=3)	
<b>Do you have any provision in place for women with disabilities to provide feedback on their care? (n=19)</b>	<b>Yes</b> 84.2% (n=16)	<b>No</b> 15.8% (n=3)		
<b>Have you any plans to develop better services for women with disabilities? (n=19)</b>	<b>Yes</b> 52.6% (n=10)	<b>No</b> 47.4% (n=9)		

## Appendix 6. Example of guidelines for women with disabilities

Area	Standard of care
<b>Maternity services</b>	Maternity services should be proactive in engaging women with disabilities and minority groups and communities, early in their pregnancy and maintaining contact before and after birth.
	The assessment and planning of services should take into account the availability of information technology equipment and networks, local transport services, access to facilities for women with physical, sensory or learning disabilities, and access for women from minority groups.
	People with disabilities, including parents and prospective parents should be consulted and be active participants in decisions relating to the planning, delivery, evaluation and monitoring of services. This includes the setting of standards and the evaluation and monitoring of services, setting targets for improvements where necessary and taking action to ensure standards are being met.
	Services should be innovative and flexible in meeting the needs of women with communication and other disabilities.
<b>Professional Issues</b>	Disability awareness and equality training should be provided for all levels of staff.
	Midwives with limited experience in caring for women with disabilities should seek advice and guidance from disability services/organisations, other professionals; colleagues and from women themselves, who are often the best source of information.
	All midwives, obstetricians and GPs must be competent to assist women with disabilities in considering their options for antenatal, birth and postnatal care and the clinical risks and benefits involved.
	Maternity services should comply with evidence-based guidelines (e.g. NICE, SIGN) in the provision of high-quality clinical care.
	Health professionals should have knowledge and awareness of specific conditions including hereditary or congenital.
<b>Access to maternity care</b>	Antenatal care should be easily accessible to all women and sensitive to the needs of women with disabilities.
	Maternity services should be flexible to meet the needs of all women including women with disabilities.
	Maternity services should ensure that they are inclusive for women with disabilities and consider their needs including communication, equipment and support needs.
	Maternity services should provide for translation, interpreting and advocacy services, based on an assessment of needs.
<b>Antenatal care</b>	Antenatal care should be provided in a variety of settings.
	Women with disabilities should be identified early, either from a G.P. referral letter or first booking interview/visit.
	The first booking interview/visit should be flexible and inclusive and the woman's preferred method of communication should be identified. At the first booking interview/visit, pregnant women with disabilities should be offered information about locally available services to allow them to choose the most appropriate options for pregnancy care, birth and postnatal care.
	The frequency and location of antenatal care should be agreed with the woman, the number of scheduled antenatal appointments should be planned in accordance with national guidelines.
	Each antenatal appointment/visit should be of appropriate duration and structured.
	Women with a disability should be offered information on the full range of options available to them throughout pregnancy,



	<p>birth and early parenthood, including locally available services, screening tests and types of antenatal and postnatal care available to them.</p> <p>Antenatal screening should be approached sensitively, with an awareness and understanding of inherited and non-inherited disabilities.</p> <p>Each woman should receive the support and advocacy of a known midwife throughout their pregnancy to promote the normal aspects of pregnancy and birth, support and to advocate for the woman.</p> <p>A detailed assessment of needs should be carried out to ensure that every woman with a disability has a flexible plan of care devised and adapted to her own particular requirements for antenatal care, birth and postnatal care. Document the agreed plan of care and communicate this to the multi-disciplinary team.</p> <p>Identify and focus on the women's strengths rather than on the disability.</p> <p>Conduct a risk assessment as required.</p> <p>Midwives should be familiar with local networks and disability organisations. Midwives should network and collaborate with a multi-professional team (e.g. obstetricians, midwives, paediatricians, public health nurse, mental health midwife, psychiatrist, community mental health teams, occupational therapist, physiotherapists, social workers, disability organisations, support groups) to facilitate multi agency support and provide inclusive care.</p> <p>Women with complex needs should be referred to appropriate professionals as soon as possible after pregnancy is confirmed.</p> <p>Women should be encouraged to bring their own aids and equipment into the hospital setting, may need to consult with hospital personnel (health and safety, infection control) in the antenatal period to discuss the same.</p>
<b>Antenatal parent education programme</b>	<p>Midwives should provide a comprehensive, flexible, creative and accessible programme of education for childbirth and parenthood to women with disabilities, their partners and families. Women with disabilities should be included in mainstream antenatal and postnatal groups and should be given an opportunity to raise concerns privately if they so wish.</p>
<b>Communication and information</b>	<p>Effective listening skills should be employed in order to ascertain information and communicate effectively with women, their partners and families.</p> <p>Identification of the woman's preferred method of communication. Remove any barriers to communication.</p> <p>Women should be offered evidence-based information and support to enable them to make informed decisions regarding their care.</p> <p>Midwives should be aware of local resources and work with women to locate relevant information as early as possible.</p> <p>Information should be provided in a form that is accessible to pregnant women who have additional needs, such as those with physical, cognitive, or sensory disabilities. Information should be available in different formats e.g. written, Plain English, audio, Braille, pictorial.</p> <p>Information should be available in different languages, with particular cultural beliefs or sensitivities appropriately reflected.</p> <p>Interpreting services, including sign language interpreters should be provided for women where English is not their first language. Relatives should not act as interpreters</p> <p>Healthcare professionals should be alert to risk factors and signs and symptoms of child abuse. If there is raised concern, healthcare professionals should follow local and statutory child protection policies.</p>
<b>Intranatal care</b>	<p>Health professionals should identify appropriate sources of equipment, aids and other supports required by the woman, her partner and the professionals.</p> <p>Address comfort measures for partner and/or support person.</p>

	Consider possibility of home birth.
<b>Postnatal care</b>	<p>A documented, individualised postnatal plan of care should be developed with the woman, ideally in the antenatal period or as soon as possible after birth. This should take account of:</p> <ul style="list-style-type: none"> <li>• relevant factors from the antenatal, intranatal and immediate postnatal period,</li> <li>• details of the healthcare professionals involved in her care and that of her baby, including roles and contact details;</li> <li>• plans for the postnatal period.</li> </ul> <p>This should be reviewed at regular intervals.</p>
	Identify and focus on the women's strengths rather than on the disability.
	New mothers with a disability should have a choice about her length of postnatal stay. Health professionals should liaise with appropriate community services and voluntary organisations as early in pregnancy as possible, in order to ensure access to available support and resources in the community when the woman is discharged home.
	Parents should be provided with accessible information on infant care, parenting skills and accessing local community support groups.
	Positive role model(s) should be identified. Women and their partner should be advised of support groups for parents with disability.
	Women should be provided with accessible information and support on their chosen method of feeding including access to peer support groups and voluntary organisations.
	Women who are taking medicines and who plan to breastfeed should receive specialist advice, based on best available evidence.
	Midwives and public health nurses should be able to support parents with disabilities in developing a basic understanding of infant attachment issues.
	Midwives should know where to source advice and information on the range of benefits and the availability of special equipment and aids for parents with disabilities.

<b>Mental Health</b>	All pregnant women should be asked about any previous history of psychiatric disorder and/or family history of serious mental illness early in their pregnancy and provided with information on pregnancy and mental health which helps them to disclose and discuss mental health issues.
	Maternity care providers and mental health care providers should have joint working arrangements in place, including arrangements for direct access by midwives, GPs and obstetricians to a perinatal psychiatrist.
	Multidisciplinary care should be available for all women with pre-existing medical, psychological or social problems that may require specialist advice during pregnancy.
	Women with an existing mental disorder who are pregnant or planning a pregnancy and women who develop a mental disorder during pregnancy or the postnatal period, should be provided with culturally sensitive information at each stage of assessment, diagnosis, course and treatment about the impact of the disorder and its treatment on their health and the health of their fetus or child.
	During pregnancy, all women who are identified as at risk of serious postnatal mental illness should be assessed by a psychiatric team. A management plan of agreed interventions and action to be taken should be document and communicated to all members of the multidisciplinary team.
	All health professionals should be able to distinguish normal emotional and psychological changes from significant mental health problems and to refer women for support according to their needs.
	Women who require to be admitted to a psychiatric hospital following delivery should be admitted to a specialist psychiatric mother and baby unit

Other relevant clinical guidelines that should be considered are –

NICE Antenatal Care: routine care for the healthy pregnant woman. Available: <http://www.nice.org.uk/nicemedia/pdf/CG062NICEguideline.pdf>.

NICE Intrapartum care: care of healthy women and their babies during childbirth. Available: <http://www.nice.org.uk/nicemedia/pdf/IPCNICEguidance.pdf>.

NICE Routine postnatal care of women and their babies. Available: <http://www.nice.org.uk/nicemedia/pdf/CG37NICEguideline.pdf>.

NICE Antenatal and postnatal mental health: the NICE guideline on clinical management and service guidance. Available: [www.nice.org.uk/nicemedia/pdf/CG45fullguideline.pdf](http://www.nice.org.uk/nicemedia/pdf/CG45fullguideline.pdf).

Royal College of Midwives (RCM) (2000) Position paper 11 a: maternity care for women with disabilities. Available: <http://www.rcm.org.uk>.

Royal College of Nursing (RCN) (2006) Meeting the Health Needs of People with Learning Disabilities: Guidance for Nursing Staff. Available: [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0004/78691/003024.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0004/78691/003024.pdf).

Royal College of Nursing (RCN) (2007) Pregnancy and disability: RCN guidance for midwives and nurses. Available: [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0010/78733/003113.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0010/78733/003113.pdf).

Royal College of Obstetricians and Gynaecologists (RCOG) (2002) Advice on planning the service in obstetrics and gynaecology: clinical standards. Available: [http://www.rcog.org.uk/resources/public/pdf/WP\\_Clinical\\_Standards.pdf](http://www.rcog.org.uk/resources/public/pdf/WP_Clinical_Standards.pdf).

Royal College of Obstetricians and Gynaecologists (RCOG) (2008) *Standards for maternity care: report of a working party*. Available: <http://www.rcog.org.uk/resources/public/pdf/maternitystandardsdatabase0608.pdf>.

Royal College of Psychiatrists (2000) CR88: Perinatal Mental Health Services: recommendations for services for childbearing women. Available: <http://www.rcpsych.ac.uk/publications/cr/cr88.html>.

## Appendix 7. Table of policies/legislation/position paper/reviews

### Table of Policies/Legislation/Position paper/Reviews – Physical and Sensory Disability

Title	Policy	Legislation	Guideline Position paper Review	Status	Content
Ireland					
Commission on the Status of People with Disabilities (1996)			√	X	Equality and inclusion of people with disabilities
Towards an Independent Future (1996)			√	X	Accessible transport system, provision of information in an accessible format for people with sensory impairment, establish regional co-ordinating committees, implement a process to evaluate the health services and appoint a Director of Services for people with a physical or sensory disability
National Disability Authority Act (1999)		√		Current	National Disability Authority – develop policies and guidelines
Equal Status Act (2000, 2004)		√		Current	Essential for equality and non discrimination
Disability Act (2005)		√		Current	Part 2 and Part 3 –accessibility to service and information, assessment of needs currently restricted to persons aged 0-5yrs
Citizen Information Act (2007)		√		Current	Assignment of personal advocate
DOHC Sectoral Plan			√	Current	Commitment to meet obligation established in provisions of Disability Act (2005)
Shaping a Healthier Future (1994)	√			Replaced	Develop local services, organisation and co-ordination of services and the implementation of initiatives to increase equity and access of service for people with disabilities
National Health Promotion Strategy (2000-2005)	√			Current	Promoting, achieving and maintaining a healthy lifestyle important for people with a physical and sensory disability – these persons must be consulted when planning, implementing and evaluating programmes to promote a healthy lifestyle
Quality and Fairness – a system for you (2001)	√			Current	Develop primary care. Team based primary care services and the provision of services in a cohesive and continuous manner
Primary care: a direction (2001)	√			Current	New model of Primary Health Care and recommends that primary healthcare centres be accessible to people with a disability. Disability training and awareness for all staff
A plan for Women's Health (1997-1999)	√			Current	Disability training and awareness. Funding available for innovative projects and approaches which improved services for women with

					disabilities
National Women's Strategy (2007-2016)	√			Current	No reference to women with disabilities within the context of maternity care
HSE Transformation programme (2007-2010)	√			Current	Developing integrated services, the configuration of hospital services and reconfiguration of resources in order to provide services within the local community
HSE National Intercultural Health Strategy (2007-2012)	√			Current	Strategy to facilitate social inclusion and equality of opportunities for people from diverse cultural and ethnicity minority groups.
<b>United Kingdom</b>					
Disability Discrimination Act (1992)		√		Amended	Duty of care – equal access, remove barriers, quality care, effective communication, change policies and practices, provide auxiliary aids, physical access, disability training and awareness
Disability Discrimination Act (2005)		√		Current	Local authorities responsibility Disability Equality Duty (DED) – develop disability equality schemes to facilitate accessibility, non discrimination and participation
Pregnancy and disabilities: RCN guidance for midwives (RCN, 2007)	√			Current	Establishes midwife's responsibility, disability awareness and training, professional behaviour and etiquette, effective communication, early assessment of needs, referral mechanism, local provision of care, appropriate information and equipment , care innovative and flexible
Maternity care for women with disabilities RCM (2000)			√	Current	Consult with women with disabilities, access to accurate, appropriate information, flexible parenting preparation classes, philosophy of women centred care
Standards for maternity care (RCOG, 2008)	√			Proposed	Standards 3, 7, 22, 26, 30 - access to maternity care, innovative and flexible services, communication and information accessible and appropriate, awareness of facilitators to prevent or overcome barriers
Maternity Matters: choice, access and continuity of care in safe services (DoH, 2007)	√			Current	No specific reference to women with disability, promotes local services, choice in type of care, where to access care and place of birth, flexible care, assessment of needs, individual care plan, information about services available
NSF for children, young people and maternity services (DoH, 2004)			√	Current	Consult with women, accessibility to built environment, sign language interpreter, recognise and overcome barriers to access, local services, information about services available, access birth environment
Doubly Disabled (DoH, 1999)			√	Current	Guide to compliance with DDA (1995), guidance on accessible services for senior NHS managers not gender specific, no reference to pregnancy
Clinical standard – advice on planning the service in obstetrics and gynaecology (RCOG, 2002)			√	Current	Sets out clinical standards in obstetrics and gynaecology, no reference to women with disabilities but discusses the provision of designated lead consultant obstetrician and clinical midwife manager in labour ward
Disability Equality Scheme – East and North Hertfordshire PCT (2006-2009)			√	Current	No reference to women or maternity care – plan to meet obligations enshrined in DDA (2005), recognise diversity,

					provision of information, disability and awareness
You can make a difference - improving hospital services for disabled people (DRC, 2004)			√	Current	Guide to compliance with duty of care set out in DDA (2005), guidelines to improve hospital services for people with disabilities – generic guide, women or maternity services not discussed
You can make a difference - improving primary care services for disabled people (DRC, 2004)			√	Current	Guide to compliance with duty of care set out in DDA (2005), guidelines to improve primary care services for people with disabilities – generic guide, women or maternity services not discussed
Creating a disability equality scheme: a practical guide for the NHS (DoH, 2006)			√	Current	Guide to compliance with DDA (2005) - advice to NHS organisations on the development of Disability Equality Scheme
Health reform in England: update and commissioning framework (DoH, 2006)			√	Current	Update on health reform for managers in NHS, focuses on commissioning NHS services
Disability Equality Scheme (2006-2009) NHS Scotland (2007)			√	Current	Strategy which sets out how NHS organisations intend to fulfil its duties within the DDA (2005)
Disability equality impact assessment and the disability equality duty (DRC, 2006)			√	Current	Compliance with DDA (2005) - a document for managers to assist in assessment of suitability of services provided for people with disability
The Disability Equality Duty and Involvement: guidance for public authorities on how to effectively involve disabled people (DRC, 2006)			√	Current	Compliance with DDA (2005) - guidance for public authorities on how to effectively involve people with disabilities
Health and the Disability Equality Duty: guidance for public authorities working in health sector in England and Wales (DRC, 2006)			√	Current	Compliance with DDA (2005) - guidance for public authorities and managers in health sector in England and Wales to promote disability equality, promoting positive attitudes, eliminating discrimination and encouraging participation of people with disabilities
Health and the Disability Equality Duty: a guide to the DED for NHS health Boards in Scotland (DRC, 2006)			√	Current	Compliance with DDA (2005) - guidance for NHS health boards in Scotland to promote disability equality, promoting positive attitudes, eliminating discrimination and encouraging participation of people with disabilities
DHSSPS Disability Action Plan (DHSSPS, 2007)			√	Current	Action plan devised by the Department of Health, Social Services and Public Services to comply with obligation of DDA (1995) to promote positive attitudes towards disability and encourage participation of people with disability
Maternity services: national for maternity services in Scotland (NHS QIS, 2005)			√	Current	Maternity care standards developed by NHS quality improvement Scotland in consultation with health professionals, does not refer to women with disabilities
A framework for maternity services in Scotland (Scottish Executive, 2001)			√	Current	Reform of maternity services, establishes principles of service organisation and principles maternity care standards indicated, does not refer to women with disabilities
Patient Access Policy – Milton Keynes Hospital (2008)	√			Current	Local policy to manage waiting list, referrals for OPD, investigations and elective surgery to achieve strategic aim of

					providing timely, accessible patient centred care, no reference to women with disabilities
National Institute for Health and Clinical Excellence: antenatal care (NICE, 2008)			√	Current	NICE clinical guideline on routine antenatal care for healthy woman during pregnancy, no reference to women with disabilities
National Institute for Health and Clinical Excellence: intra-partum care (NICE, 2007)			√	Current	NICE clinical guideline on healthy woman who are giving birth, no reference to women with disabilities
National Institute for Health and Clinical Excellence: postnatal care (NICE, 2006)			√	Current	NICE clinical guideline on postnatal care for healthy mother and healthy baby for 6– 8 weeks after birth, does not refer to women with disabilities
<b>Canada</b>					
Canadian Human Rights Act (1977)		√		Current	Prohibits discrimination on the grounds of disability
Canadian Charter of Rights and Freedoms (1982)		√		Current	Equality of rights - right to equality and non discrimination
Women's Health Strategy (1999)			√	Current	Policies need to be responsive to women, provision of effective healthcare services, promotion of good health, collaboration amongst care providers, integrated services, access to environment, refers to Canadian perinatal system, no reference to women with disabilities
Family – centred maternity and newborn care: national guidelines (2000)			√	Current	Guideline with 13 guiding principles which form the bases of family centred maternity and newborn care, birth is considered as a normal, healthy process, unique to each woman; care is administered within the context of the family unit; the women's autonomy and the concept of informed decision making is promoted and all care is based on best evidence and practice, no reference to women with disabilities
Advancing the Health of Girls and Women in British Columbia (2004)			√	Current	Provincial women's health strategy – compliance with national women's health strategy, no reference to women with disabilities
Making every Mother and Child Count (Public Health Agency Canada, 2005)			√	Current	Improve services and care to reduce rates of maternal and infant morbidity and mortality rates
The Accessibility for Ontarians with Disabilities Act (AODA, 2005)		√		Current	People with disabilities have a right to accessible services, information and built environment – concentrates on employment and transportation but provisions applicable to health
A National Birthing Initiative for Canada (2008)			√	Proposed	Framework for family centred maternity and newborn care, integrated services, pan Canadian initiative, no reference to women with disabilities
In Unison: a Canadian approach to disability issues (1997)	√			Current	Principles of equality, inclusion and independence, building block for subsequent policy development – not gender specific no reference to healthcare
Canada Prenatal Nutrition Program (1994)	√			Current	Policy to improve health of pregnant women, focus on at risk pregnant women – local services, increase accessibility to services
Advancing the Inclusion of People with Disabilities (2006)			√	Current	Annual report on Canadian governments progress on disability, focus on disability related initiatives, no reference to women or



					reproductive healthcare
Women with Disabilities in Nova Scotia: a statistical profile (2006)			√	Current	Statistical profile – no relevance to provision of services
Tips for women's service providers working with women with disabilities (2001)			√	Current	Effective communication and provision of accessible information discussed in context of physical abuse, no reference to maternity or reproductive care
Society of Obstetricians and Gynaecologists of Canada (2003)	√			Current	Policy statement to embrace diversity and promote equity of care
<b>Norway</b>					
National Health Plan for Norway (2007-2010)	√			Current	Accessible services for women with physical disability – services information and transport, community based local hospitals, risk assessment to determine low or high risk pregnancy if low risk delivery in local hospital, provision of postnatal care in local health centres – staff with multidisciplinary team
Act of 2 <sup>nd</sup> July 1999 no. 64 relating to Health Personnel etc.		√		Current	Training and education of healthcare personnel
Act of 2 <sup>nd</sup> July 1999 no. 63 relating to Patient's Rights		√		Current	Patients' rights when accessing healthcare
Programme of Action for Universal Design			√	Current	Universal design and accessibility for all
<b>Netherlands</b>					
Equal Treatment on the Grounds of Disability or Chronic Illness Act (2003)		√		Current	Prohibits discrimination on grounds of disability applies to employment, public transport, vocational and professional education, no reference to health or women with disabilities
Primary Health Care in the Netherlands (2005)	√			Current	Document which discusses the structure, organisation, funding, regulation of Dutch health system
<b>Sweden</b>					
From patient to citizen: a national action plan for disability policy (2000)	√			Current	Reform society's attitudes towards people with disabilities, remove barriers to participation, prevent discrimination, main focus is integration of people with disabilities into society, healthcare not included
The Health and Medical Service Act (1982)		√		Current	Refer to assistive devices for people with disabilities
Guidelines for accessibility: breaking the barriers (Handisam, 2004)			√	Current	Guideline for employers to assist them in the development of policy to comply with requirements of disability policy,
The Disability Ombudsman Act (1994)		√		Current	Facilitates the appointment of a Disability Ombudsman – mechanism for redress of person experiences discriminatory practices
<b>United States of America (US)</b>					
The American with Disabilities Act (ADA) (1990)		√		Current	Title II – programs must be accessible, physical accessibility, building standards, use of appropriate auxiliary aids, sign language interpreter, provision of information in appropriate format
ADA: communicating with people who are			√	Current	Provides guidance to health professionals on appropriate

deaf or hard of hearing in hospital settings (2003)					measures to ensure effective communication with deaf or hard of hearing patients
Prenatal Care Assistance Program (PCAP)(2000)	√			Current	No reference to women with disabilities, outreach services, ongoing assessment of maternal and fetal health during pregnancy, individual care plan developed and updated regularly, co-ordinated services, health and parent education classes to all women, psychological assessment on all women, postnatal follow up and support
<b>Australia</b>					
Commonwealth Disability Discrimination Act (DDA) (1992)		√		Current	Prohibits discrimination on grounds of disability, promote equality of people with disabilities, Section 23 access to services, develop disability standards and action plans
Disability Services Act (1991)		√		Current	Legislative framework which governs provision of disability services to people with a disability
Disability Act (2006)		√		Current	Legislative framework which governs provision of disability services to people with a disability in Victoria
Queensland Disability Services Act (2006)		√		Current	Legislative framework which governs provision of disability services to people with a disability in Queensland
Disability Act (2006): policy and informational manual (2007)		√		Current	A guide for service providers outlining their duty of care established under the Disability Service Act (2006) in the provision of disability services
Commonwealth Disability Strategy (1994)	√			Current	Practical guidance to organisation and services providers on the removal of barriers to services, services, facilities and programs must be accessible to people with disability, service providers obliged to meet requirements of CDS
Report on the evaluation of the Commonwealth Disability Strategy (FaCSIA, 2006)			√	X	Outlines outcomes achieved within the first 5 years of implementing the Disability Strategy, attitudes towards people with disabilities have improved, better accessibility to built environment, increased awareness of people's needs, information about services is more accessible, progress on implementation slow
South Australian Disability Action Plan (2008-2013)	√			Current	South Australian - plan to address the obligations set out in the DDA (1992), sets out measures to ensure accessibility to built environment, effective communication, disability training and awareness, provision of information in appropriate formats, use of auxiliary aids and integrated services
South Australian Women's Health Policy (2005)	√			Current	Service providers must ensure that services provided during pregnancy, birth and motherhood to women, services must be consistent, comprehensive, well co-ordinated, women centred, flexible and safe, women should have access to information on reproductive issues and practical parenting assistance
South Australian Women's Health Action Plan: initiatives for 2006/7	√			Current	Sets out priority areas requiring action – need to develop strategies that focus and address the needs of women with disabilities with emphasis on reproductive and sexual health

ACT Women's Plan (2004)	√			Current	Services must be accessible to all women, conduct individual needs assessment, access to information about services provided, physical accessibility for all, no reference to women with disabilities
Victorian Standards for Disability Services (2002)	√			Current	A set of standards that service providers are required to adhere to when providing disability services in Victoria, not gender specific, not related to maternity services
Queensland Disability Services Plan (2007-10)	√			Current	Queensland - plan to address the requirements of the DDA (1992), when providing disability services, sets out measures to ensure accessibility to built environment, individual assessment of needs, disability training and awareness
Re-birthing: report of the review of maternity services in Queensland (2005)			√	Current	Proposes a new strategy of integrated maternity care – Maternity Care 2010, women with special needs must have their needs met, no reference to women with disabilities
Victoria State Disability Plan (2002-2012)	√			Current	Priority strategy 5: make public services accessible, set out a commitment to ensure accessibility to public services, no reference to women or maternity services
Code of Ethics for Midwives in Australia (2008)			√	Current	Code outlining the ethical conduct, behaviour and interaction midwives are required to adhere to when engaging and interacting with all women, no reference to women with disabilities
Code of Professional Conduct for Midwives in Australia			√	Current	A set of national standards of professional conduct for midwives
Victorian Women's Health and Wellbeing Strategy (2002-2006)	√			Current	Recognise diversity of needs among women – embrace diversity, encourage participation of women, enhance safety and security, improve women's mental and emotional health, accessible health information and services
Victorian Charter of Human Rights and Responsibilities: civil and political rights explained (2008)	√			Current	Promotion of equality and non discrimination
Promoting Independence: disability action plans for South Australia: 7 <sup>th</sup> annual report on implementation (2007)			√	X	The report identifies the progress achieved in various government departments following implementation of the disability action plans.
Improving maternity services: working together across Western Australia (DoH, 2007)	√			Current	A framework to attain a high standard maternity service, community based antenatal, comprehensive parent education programme, co-ordinated and integrated of services, continuity of carer, provision of information in appropriate format to facilitate choice and informed decision making, no reference to women with disabilities
Our promise to you: delivering great service to all Australians (2007)			√	X	Guides services provided by Medicare
Women with Disabilities Australia: policy paper on advocacy (2008)	√			Proposed	Paper discussing the importance of adopting a model of self advocacy for all women with disabilities, WWDA have committed to undertaking a number of initiatives to advance the human rights of women with disabilities

Disability Services Access Policy (2007)	√			Current	Information resource for people with disabilities and service providers, discusses how a person can apply for disability services, the assessment process which will be undertaken and the redress mechanisms open to the person
Review of the role of the ACT government as a disability service provider (2007)			√	X	Discuss the ACT government's role in the provision of disability services, refer to DDA (1991)
Women's Health Matters: from policy to practice (2006-10)			√	X	A discussion paper which identifies the priority areas that will be addressed in women's health plan, advocates for a sexual and reproductive health strategy
First steps forward: South Australia health reform program (2003)			√	X	Provides information on the health reform programme, reproductive health services not discussed
Better information and communication practices			√	X	Provides guidance to service providers on the provision of information in appropriate format and how to effectively communicate with women with a disability
Better Physical Access			√	X	Provides guidance to service providers on how to achieve an accessible physical environment for people with disabilities
Queensland Health Strategic Plan (2000-10)	√			Current	Ten-year strategic plan for health services
<b>New Zealand</b>					
New Zealand Public Health and Disability Act (2000)		√		Current	Part 2 establish ministerial responsibility to develop a health strategy and a disability strategy
New Zealand Disability Strategy (2001)	√			Current	Objective 14 refers to women - improving the opportunities for women with disabilities to access appropriate disability services which will enhance their quality of life , treat women with dignity and respect, provide appropriate information about the services and how to access the services, effective communication accessible buildings, reproductive services not discussed
Work in Progress: annual report on the implementation of NZ Disability Strategy (2007)			√	X	Report on the progress made on the implementation of Disability Strategy, progress achieved on accessibility of services, access to built environment, disability training and awareness
New Zealand Health Strategy (2000)	√			Current	Equitable and fair health service, accessible and appropriate services, information about services are accessible to all
Primary Health Care Strategy (2001)	√			Current	Alternative choices, maternity care provided locally, continuity of carer, integrated services, information about services available to all, consult with disability organisation to remove barriers to care for people with disabilities
Action Plan for New Zealand Women (2004)	√			Current	Sets the improvement of access to services as a goal for women, including those with a disability, but does not discuss action(s) to achieve this goal
Maori Health Strategy (2002)	√			Current	Recognises the importance of reducing inequities in health service provision, services need to be more accessible, timely, culturally appropriate care, remove barriers experienced by women with disabilities and encourage these women to participate more in planning of care

The Pacific Health and Disability Action Plan (2002)	√			Current	Focus is on indigenous minority population, services need to be more responsive to the needs of a diverse population, improve access to care, conduct a needs assessment, develop culturally appropriate guidelines for assessment process, foster inclusiveness
Sexual and Reproductive Health Strategy (2002)	√			Current	Primary and specialist health services should be accessible and responsive to the diverse needs of people with disabilities
New Zealand Disability Strategy Implementation Review (2001-2007)			√	X	Reports on the progress made in the 6 years since the inception and implementation of the Disability Strategy. Improvements noted in accessible environments, provision of information in alternative and appropriate formats, more positive attitudes towards people with disabilities, services more accessible; however, progress is slow, funding assigned to implementation programme is insufficient and there is no co-ordinated plan for implementation
New Zealand Public Health and Disability Act (2000)		√		Current	Part 2 establish ministerial responsibility to develop a health strategy and a Disability Strategy
Maternity Services: notice pursuant to section 88 of the New Zealand Public Health and Disability Act (2000)		√		Current	Sets out eligibility criteria practitioners must meet before applying for funding for services rendered
The New Zealand Carer's Strategy and Five year action plan (2008)	√			Current	A framework of principles that will guide policy development and service delivery
Ministry of Health: disability services strategic plan 2008-2010				Current	Sets out the direction for disability support services - outcome based approach advocated
New Zealand Sign Language Bill (2004)		√		Current	Act which officially recognises New Zealand Sign Language as preferred language of deaf people
Child Health Strategy (1998)	√			Current	Framework to advance the health wellbeing of children
<b>European Union (EU)</b>					
2010: a Europe accessible for all (2003)	√			Current	Access to built environment will facilitate inclusiveness, participation, all polices should consider accessibility to environment
Disability Action Plan (2006-15)	√			Current	A framework which policy makers in member states can refer to when designing, implementing and evaluating disability policies and strategies
<b>United Nations (UN)</b>					
UN Convention on the Rights of Persons with Disabilities (2006)		√		Proposed	Signatory states must take appropriate action to ensure that people with disabilities have access to the physical environment, to appropriate methods of communication, information must be provided in accessible and appropriate formats, states must ensure that people with disabilities are afforded the same range, quality and standard of healthcare as non disabled persons
<b>Denmark</b>					
Danish Disability Policy: equal opportunities through dialogue (2002)	√			Current	Background to current disability policy – discusses policy in relation to accessibility, education, work and social security,

					supportive measures, Family life and personal integrity, health, housing, transport and culture. Maternity services not discussed
Report on health and long term care in Denmark (2005)				X	Refers to patients' right when accessing general healthcare
Health care in Denmark (2002)				X	Refers to pregnancy and maternity but no reference to women with disabilities

**Table of Polices/Legislation/Position paper/Reviews – Perinatal mental health**

Title	Policy	Legislation	Guideline Position paper Review	Status	Content
<b>Australia</b>					
Perinatal Mental Health Initiative (2006).			√	Current	Screening and assessment of psychosocial risk factors for depression
Beyondblue: the national depression initiative (2007)			√	Current	Routine assessment of depression and related problems during pregnancy and the postnatal year together with training for GP's, midwives, obstetricians, maternal and child health nurses, child protection workers and social workers
College Statement Royal Australian and New Zealand College of Obstetricians and Gynaecologists (2007)			√	Current	Maternity staff is responsible for identifying symptoms of depression during pregnancy. Screening tools, care plans and early intervention to prevent postnatal depression
<b>United Kingdom</b>					
Why Mothers Die (2004)			√	X	Main driver for policy recommendations involving the routine screening of all women for perinatal mental health disorders during pregnancy. Suicide and mental illness were main reasons for indirect maternal deaths in the UK
Antenatal and Postnatal Mental Health: Clinical Management and Service Guidelines (2007)			√	Current	Women should be screened for past or present severe mental illness and for depression. Clinical networks should be instituted for prenatal mental health services
Postnatal Depression and Puerperal Psychosis. SIGN publication No 60 (2002)			√	Current	Highlights best clinical practice in relation to postnatal depression and puerperal psychosis
<b>Canada</b>					
The Family Centred and Newborn Care: National Guidelines (2008)			√	Current	Recommends the introduction of psychosocial risk assessments for every women during prenatal care
British Columbia Reproductive Care Programme. Reproductive Mental Health Guideline 2 (2003)			√	Current	Outlines best practice for the care of women with mental illness, their partners and their children during the perinatal period using a bio psychosocial-spiritual framework

Interventions for postpartum depression. Registered Nurses association of Ontario (2005)			√	Current	Initiation of preventative measures in the early postnatal period; confirming postnatal depression with the Edinburgh Postnatal Scale (EDPS)
<b>Ireland</b>					
A Vision for change: report of the expert group on mental health policy (2006)			√	Current	One adult psychiatrist and one senior nurse with perinatal experience should be appointed to act as a national resource in the provision of care to women with severe perinatal mental health problems
<b>Denmark</b>					
Healthy Development Throughout Life-the layers and strategies for public health policy of the Government of Denmark (2002)			√	Current	Recommended early interventions for postpartum depression and emphasised the need to protect the mother child relationship
<b>United States of America (US)</b>					
The perinatal Mental Health Disorders Prevention and Treatment Act (2008)		√		Current	Maternity hospitals must provide complete information about perinatal mental health disorders in the antenatal period and each woman is invited to complete a mental health assessment
<b>New Zealand</b>					
Review of the first nine months of the National Depression Initiative (2008)			√	X	Pregnant women and those with new babies targeted by a campaign involving free advertising, free phone service, websites. Midwives are the main caregivers and are best placed to monitor and advise women about postnatal depression



**Table of Polices/Legislation/Position paper/Reviews – Intellectual Disability**

Title	Policy	Legislation	Guideline Position paper Review	Status	Content
<b>Ireland</b>					
Disability Act (2005)		√		Current	Section 28 – Public bodies must ensure that information is in accessible formats for people with an intellectual disability.
Vision for Change (2006)	√			Current	No specific reference to women / mothers with an intellectual disability and maternity care.
National Health strategy plan (2000)	√			Current	No specific reference to women / mothers with an intellectual disability and maternity care.
DOHC Sectoral Plan (2007)				Current	According to the Sectoral Plan (Department of Health and Children, 2007a) and the Disability Act 2005 Year 1 Review (Department of Health, 2006a), the Health Service Executive have provided guidance and protocols to services on how to ensure communications are accessible to people with an intellectual disability. The Health Service Executive's National Communications Unit has instructed all services to review their communications to ensure they comply with Section 28 of the Disability Act 2005, in terms of people with intellectual disabilities.
<b>United Kingdom</b>					
Pregnancy and disabilities: RCN guidance for midwives (RCN 2007)	√			Current	Pregnancy and Disability (Royal College of Nursing, 2007) offers limited insight into the needs of women / mothers with intellectual disabilities accessing maternity care. This advisory document acknowledges that this group of women become pregnant and access maternity services. It encourages professionals to work collaboratively with professionals in the intellectual disability field and to ask parents / cares what is the best ways of communicating with the person with intellectual disabilities, rather than encouraging client empowerment and self advocacy for this group of women.
Maternity care for women with disabilities RCM (2000)			√	Current	Acknowledges that women / mothers with intellectual disabilities may have specific maternity care needs but does not specifically refer to what those needs are or how they are best met. It does not offer best practice advice on how this should be legally addressed. No reference is made to the various 'Consent Legislation' within the UK i.e. England and Wales – Mental Capacity Act 2005; Northern Ireland – Guidance on Consent to Treatment 2003 and in Scotland – Adults with Incapacity Act 2000 (Scottish Executive, 2000a).
Maternity Matters: choice, access and continuity of care in safe services (DoH, 2007)	√			Current	To ensure that discrimination is not affecting this, and other groups of women, Maternity Matters reminds maternity services of their statutory duties under the Disability Discrimination Act (Parliament, 1995) e.g. that organisations need to conduct disability and gender equality impact assessments as a central component of policy development and service delivery so as to ensure equality for all at every level.

					Briefly refers to women / mothers with intellectual disabilities twice. Firstly, in the introduction, it reinforces Maternity Standard 11 within the National Service Framework for Children, Young People and Maternity Services (Department for education and skills & Department of Health, 2004 & Department of Health, 2004a&b) i.e. the need for maternity care to be accessible to all women and address the specific needs of women / mothers with intellectual disabilities. No reference is made to what these women / mothers' needs are in this context, or how they are best met, but the strategy does acknowledge difficulties in gathering data on disability groups. The second brief reference advises partnership working between maternity and intellectual disability services, such as multidisciplinary community intellectual disability teams to help ensure this.
A framework for maternity services in Scotland (Scottish Executive, 2001)			√	Current	Reference made about people with an intellectual disability and advises partnership working between maternity and intellectual disability services, such as multidisciplinary community intellectual disability teams to help ensure this.
'You and Your Baby' (CHANCE, 2004)			√	Current	In terms of accessible information, the Department for Education and Skills have funded the publication of 'You and Your Baby' (CHANCE, 2004), but this is not usually given to parents with intellectual disabilities (Working together with Parents, 2008).
Report of the DRC Formal Inquiry panel to the DRC's formal investigation into the inequalities in physical health experienced by people with mental health problems and people with learning disabilities. London, Disability Rights Commission, 2006).			√	Current	The Disability Rights Commission highlight the need for the Nursing and Midwifery Council and Nursing Council of Deans to develop pre and post registration curriculum materials on intellectual disability equality/access. The Disability Rights Commission also highlights that the needs of people with intellectual disabilities have not been a priority on the national agenda (Disability Rights Commission, 2006).
Valuing People (England) (Department of Health, 2001)			√	Current	National Strategy for people with an intellectual disability. Principles are rights-based, broad and mainly aspirational. No specific reference made on maternity care. No specific reference to people with an intellectual disability and maternity care.
The Same as You? (Scotland) (Scottish Executive, 2000b);			√	Current	National Strategy for people with an intellectual disability. Principles are rights-based, broad and mainly aspirational.No specific reference made on maternity care. No specific reference to people with an intellectual disability and maternity care.
Fulfilling the Promises (Wales) (The Welsh Assembly, 2001)			√	Current	National Strategy for people with an intellectual disability. Principles are rights-based, broad and mainly aspirational. No specific reference made on maternity care. No specific reference to people with an intellectual disability and maternity care.
Equal Lives (Northern Ireland) (Department of Health, Social Service and Public Safety, 2004)			√	Current	Review of Mental Health and Learning Disability Services in Northern Ireland. No specific reference to women / mothers with an intellectual disability and maternity care.

The Bamford Review (Northern Ireland) (Department of Health, Social Service and Public Safety, 2007)			√	Current	Review of Mental Health and Learning Disability Services in Northern Ireland. No specific reference to women / mothers with an intellectual disability and maternity care.
Meeting the health needs of people with learning disabilities (Royal College of Nursing, 2006).			√	Current	Guidance for nursing staff. No specific reference to people with an intellectual disability and maternity care.
<b>Norway</b>					
National Health Plan for Norway (2007-2010)	√			Current	In terms of the intellectual disability population, the National Health Plan for Norway (2007-2010) highlights the need for greater patient involvement in the development of health services, including maternity care. It acknowledges that some people with intellectual disabilities may not be best able to ensure their needs and rights are fully met and therefore encourages services to make greater use of relatives as advocates and also promotes the role of patient organisations in policy and service development. The Ministry of Health and Care Services also recognises the limited knowledge base of many health and social care professionals in meeting the care needs of people with intellectual disabilities.
<b>New Zealand</b>					
Maori Health Strategy (2002)	√			Current	No specific reference to people with an intellectual disability.
The Pacific Health and Disability Action Plan (2002)	√			Current	No specific reference to people with an intellectual disability.
New Zealand Disability Strategy Implementation Review (2001-2007)			√	X	Has agreed to continue funding the advocacy group 'People First' for people with intellectual disabilities.
Ministry of Health: disability services strategic plan 2008-2010			√	Current	A 'plain-language' version of the Health and Disability Code of Rights for people with intellectual disabilities has been produced by the Health and Disability Commissioner
Progress in implementing the New Zealand Disability Strategy 2003-2004. Fourth Annual report from the Minister for Disability Issues to the House of representatives. (Office of Disability Issues, 2005)			√	Current	Minister of Disability Issues states there is evidence that the response to the sexual activity and reproductive health of women with intellectual impairment has been 'overmedicalised and over-managed'.  Recognises the limited health promotion and illness prevention information in accessible formats.
A Review of the Health and Disability Act 1994 and the Code of Health and Disability Services Consumers Rights.			√	Current	Reports that the Health and Disability Commissioner (HDC) has developed easy-read posters and pamphlets for people with intellectual disabilities and established a database of advocacy services in partnership with the Office for Disability Issues, and the Human Rights Commission (Health and Disability

A report to the Minister of Health (Health and Disability Commissioner, 2004)					Commissioner, 2004).
Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (ID(CCR) Act 2003)		√		Current	Provides a legislative framework for meeting the needs of people, as defined by Section 7 (ID(CCR) Act 2003) as having an intellectual disability, and been charged with, or convicted of, an imprisonable offence whether or not they are subject to the criminal justice system (Ministry of Health, 2004 p.1). The Act and the Ministry of Health's guides accompanying it do not explicitly make reference to maternity care.
Ministry of Health (2004a) A Guide to Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 Wellington, Ministry of Health.			√	Current	A Guide to Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. No specific reference to women / mothers with an intellectual disability and maternity care.
Ministry of Health (2004b) Guidelines for the role and function of Care Managers under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. Wellington, Ministry of Health.			√	Current	Guidelines for the role and function of Care Managers under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003). No specific reference to women / mothers with an intellectual disability and maternity care.
Ministry of Health (2004c) Guidance for the role and function of Special Assessors under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. Wellington, Ministry of Health.			√	Current	Guidance for the role and function of Special Assessors under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. No specific reference to women / mothers with an intellectual disability and maternity care.
Ministry of Health (2004d) Guidelines for Cultural Assessment – Māori Under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (Ministry of Health, 2004).			√	Current	Guidelines for Cultural Assessment – Māori Under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. No specific reference to women / mothers with an intellectual disability and maternity care.
You have Rights (Ministry of Health, 2004)			√	Current	Information to help people with an intellectual disability understand compulsory care and how it might affect them and their rights. No specific reference to women / mothers with an intellectual disability and maternity care.
Final Report – Review of Maternity Facility Access Agreement (Ministry of Health, 2007)			√	Current	Review of Maternity Facility Access Agreement (Ministry of Health, 2007). No specific reference to women /mothers with an intellectual disability.