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The Strengths and Weaknesses of Publicly-funded Irish Health Services Provided to Women with Disabilities in Relation to Pregnancy, Childbirth and Early Motherhood

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Executive Summary

1. Introduction

This study, part of a 3-part project, was commissioned by the National Disability Authority (NDA), in a joint initiative with the National Women's Council of Ireland (NWCi), to explore the strengths and weaknesses of publicly-funded health services in Ireland provided for women with disabilities in relation to pregnancy, childbirth and early motherhood. The report presents the findings of a nation-wide study and complements the 2 companion documents forming the first 2 sections of the study, also commissioned by the NDA. The first of these was a comprehensive 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, 2009a). The second (Begley et al, 2009b), presents a review of Irish and international social policies relating to the provision of services for women with disabilities during pregnancy, childbirth and early motherhood. Together, these 2 documents outline the legal and practical provision of publicly-funded health services for women with disabilities in Ireland and 9 other countries, and provide the background for this detailed exploration of women's views and experiences of the services they received during pregnancy, childbirth and early motherhood.

2. Background

In 2008, the number of births in Ireland was 75,065 (Central Statistics Office, 2010), which is the highest number recorded since 1950. Maternity care is provided through 20 maternity hospitals/units, 19 of which are publicly funded. The number of women of child-bearing age with a disability is unknown, but figures from the Irish National Disability Survey show that approximately

20,000 women aged 18-34 and about 18,500 women aged 35-44 had a disability in one or more of the 9 categories used in the survey (Central Statistics Office, 2006). The most frequently-cited conditions for women of childbearing age were mental health conditions, pain, mobility, intellectual and learning disability, and difficulties in remembering and concentrating.

Over the past 2 decades, childbirth in Ireland has become more medicalised (Wagner, 2001; Devane et al, 2007; KPMG, 2008), and women with disabilities may therefore be at risk of being viewed through a medical lens solely because of their particular disability. A review of the salient international literature relating to the care of women with all types of disabilities suggests that society has undervalued women with disabilities, has exerted control over their sexual and reproductive lives and, in many cases, has exacerbated their difficulties. Mothers with intellectual disabilities or mental health difficulties, in particular, are often separated from their children, whether or not there is evidence of risk of harm (Begley et al, 2009a). A review of national policies in 10 countries demonstrated that, with the exception of the United Kingdom (UK), all countries lacked definitive policies relating to the care of women with disabilities when accessing maternity care (Begley et al, 2009b).

3. Aim and objectives

3.1. Aim

To explore the strengths and weaknesses of publicly-funded Irish health services provided to the following groups of women:

- (a) Women with a visual impairment (V)
- (b) Women with a hearing impairment (H)
- (c) Women with a physical disability (P)
- (d) Women with a mental health difficulty (M)
- (e) Women with an intellectual disability (ID)

3.2. Objectives

- a) To ascertain and explore the views and experiences of women with disabilities, throughout the country and across all socio-economic groupings, in relation to
 - the strengths and weaknesses they encountered in publicly-funded Irish health services during pregnancy, childbirth and in the first 2 years of motherhood,
 - their experiences of accessing general practitioners, practice nurses, midwives, obstetricians, neonatologists, paediatricians, allied health professionals, public health nurses and public health doctors, health care workers, family support workers, and
 - the service they received;
- b) To seek and discuss the views of the relevant service providers as to strengths and weaknesses of the services provided and their opinion on the development required;
- c) To make clear recommendations as to how the experience of engaging with the various publicly-funded Irish health service providers during pregnancy, childbirth and early motherhood can be improved for women with disabilities, and to do this in such a way as to maximise the likelihood of the report influencing policy-making.

4. Study methods

4.1. Study design

A qualitative descriptive design was used, employing individual interviews with women from the 5 different disability strands of the study, and focus group interviews with health professionals engaged in the provision of services for this population. Full details of the methodology of this study are contained in Appendix 2.

4.2. Recruitment

Recruitment for the study began on 10th March 2008 and ceased on 10th November 2009, with 78 women included, 20 in the mental health strand, 18 each in the physical disability, hearing impairment, vision impairment groups and 4 in the intellectual disability strand of the study. A total of 81 individual taped interviews were undertaken, as 1 woman in the mental health strand was interviewed 3 times, and 1 woman in the intellectual disability strand was interviewed twice. Full details of all women taking part are given in Chapter 1.

Thirty people participated in 6 focus group discussions. Four focus groups comprised of a variety of professionals where the focus was on all 5 disability strands of the study, while the remaining 2 were disability specific; 1 focused specifically on mental health issues and the other on intellectual disability services. Full details of all focus group participants are given in Chapter 7.

4.3. Data analysis

All interviews were recorded, transcribed in full, imported into NVivo 8 and analysed using the constant comparative method. SPSS was used to conduct descriptive analysis on the demographic data.

4.4. Rigour

Data were collected from multiple sources. Negative case analysis, peer debriefing and member checking were also employed. An example of the data analysis procedure is included in Appendix 6.

4.5. Ethical issues

Ethical approval was received from the Research Ethics Committee of the Faculty of Health Sciences, Trinity College Dublin and all relevant health service providers. The rights and dignity of women were respected throughout

by adherence to models of good practice related to recruitment, voluntary inclusion, informed consent, privacy, confidentiality, notice of withdrawal without prejudice and the prevention of psychological and physical harm.

5. Findings and discussion

5.1. The current models of maternity care

Although the focus of this study was to explore the experiences of women with a disability accessing maternity care and early motherhood services specifically, some of the findings may apply to people without disability who are accessing health services in general. The findings indicate a variation in the services available to women with disabilities and this was dependent on a number of factors including geographical location, co-location of the maternity unit with other specialist services, infrastructure of services and professional attitudes. Weaknesses identified included that, for some expectant women and mothers with mental health issues or intellectual disability, specialist services within the maternity care sector were almost non-existent. Specialist mental health services were only available in two of the 19 maternity units (both based in Dublin) and no specialist services were identified for women with an intellectual disability. When services were available they were fragmented and un-coordinated, and choices to access a specific model of maternity care were constrained significantly by lack of resources and no strategic focus for care planning. The attitudes displayed to women in this study by some health professionals also impacted negatively on women's experiences of care.

There was a focus on medicalisation within maternity care services and the perceived impact of the woman's disability limited choices and, for some expectant women and mothers, this meant that their choice of birth was overridden by the professionals' decisions, thus reducing maternal autonomy. For example, when some women with a physical or sensory disability expressed a wish to give birth at home they met resistance from some professionals, a few going so far as to

threaten to withdraw care if the woman proceeded with her plan. Women with a physical and sensory disability commented particularly on the lack of local availability of services, and inflexibility in appointment times leading to significant difficulties travelling to and from the maternity unit. It appears that women with a disability may be doubly disadvantaged when accessing maternity services as there is a lack of accessible public transport. Some women reported having to travel by taxi as appointments were scheduled outside of the availability of public transport, with inherent cost implications being borne by the woman. Ideally access to midwifery-led care, which included home visits, would have ameliorated this issue.

Many women spoke of the lack of knowledge amongst maternity care staff regarding their particular disability and the need for an individual package of care to be developed in partnership early in their pregnancy. For women with a mental health issue, when access to specialised services was available, women reported on the positive impact on their wellbeing. Access to specialised services was contingent upon geographical location and good liaison between maternity care and mental health service providers. Women with limited or no access to publicly-funded specialised psychological services had to resource these supports independently, which had significant financial implications for them. Women with an intellectual disability appeared to be more supported by social workers and others within specialist intellectual disability services. Case conferences were a routine component of antenatal care for these women, and these were helpful in ensuring continuity of care and access to appropriate services as required.

Similar concerns were expressed by women in the postnatal period where services were sourced and accessed opportunistically and on an *ad hoc* basis. For example, mothers with disabilities were advised by hospital staff that support would be provided on discharge from the unit/hospital through the public health nurse. Yet in reality, a poorly resourced community service was unable to deliver on this promise. For some women, inter-professional referrals did occur, but there was an absence of a clearly established link

between the statutory and voluntary agencies, which have the potential to provide significant support and advice to women with a disability in pregnancy and motherhood. A similar lack of collaboration between agencies is prevalent in the literature and ‘falling between stools’ is frequently reported in disability studies.

The lack of services to women after birth also raised concerns for the new mothers who experienced an absence of publicly-funded community postnatal care services by midwives. In recent times, there has been an increase in community-based midwifery-led care provision in the form of DOMINO¹ schemes, Early Transfer Home (ETH) schemes, community antenatal and postnatal clinics and 2 midwifery-led units. However, for women not accessing these specific services, there is no publicly-funded community midwifery service in Ireland. Currently, the State makes provision for one statutory visit to the mother and baby in the community by the Public Health Nurse (PHN). This single visit usually takes place in the first week following birth, and the number and timing of further visits, and/or referral to other services, are at the discretion of the PHN. Regulations related to the education and training of a PHN no longer require a midwifery qualification. In addition, there is no requirement for a children’s nursing or mental health qualification, which may have consequences on the care delivered in the medium to long term. Services for families who need support with early child care vary significantly across the country. Women in this study accessed such services by private funding, or by going to another country. This lack of community services provision for mothers and children is a key deficit within health care services in Ireland, where the community nursing services are currently under review. Often the focus of community support is on children in need rather than on

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

families who require interventions and support and is provided by voluntary agencies, each of which has its own specific agenda and client group.

Maternity services should implement and develop further inter-organisational communication to underpin service development if women with disabilities are to receive care that meets their individual needs.

5.2. Infrastructure

Although a centralised approach to the planning and delivery of maternity services is the dominant model in Ireland, the 3 Dublin maternity hospitals in particular have been identified as having ‘ageing infrastructures that are not designed to deliver the range of maternity services required today’ (HSE, 2005:11). Strengths identified in this study indicate that, in compliance with the Disability Act (2005), some positive changes to the physical infrastructure to accommodate women with disabilities to access the maternity units reasonably, have been undertaken. The Act also requires that maternity services adjust policies, practices and procedures to meet the needs of women with disabilities and this may include adaptation of equipment. It is appropriate and timely that maternity units address outstanding issues in relation to the physical build in any new developments, as weaknesses identified by this study included specific issues identified by women that continue to cause difficulty. For example, reception desks in clinics were frequently too high for wheelchair users to make contact with staff, and examination couches and baby cots were not always height adjustable. However, a strength identified was that some staff attempted to address the woman’s individual needs by sourcing the appropriate equipment to support independence with parent education skills.

As a consequence of a poorly resourced community care service, and the sometimes poor liaison between hospital and community staff, equipment and support personnel needed to maintain and foster independence were not always available once the mother and baby were discharged home. This was compounded further by the lack of liaison between the maternity and health and social welfare services at times. Some women therefore had to access support elsewhere, with a

few having to depend on others or even pay for alternative care supports. Two women found the services so lacking that they left the jurisdiction to access care elsewhere. The issues of crossing borders to access health care in Ireland has also been reported by Stewart-Moore (2009).

5.3. Communication

A major weakness identified was that some women in this study experienced significant practical difficulties when communicating with health care staff at all stages of their experience of maternity services from confirmation of pregnancy to discharge and care at home. Verbal and written communication was the primary mode of interaction with staff and services for women with sensory disabilities, despite their impairment. For example, women with visual impairment had little access to written information in a usable format such as Braille. Women with hearing impairment experienced difficulties making contact with the healthcare provider to arrange appointments, as text and fax options, for example, were not always readily available. Contact with the emergency services was an issue of concern for women with a hearing impairment as they were not in a position to phone for an ambulance, and needed to depend on others for assistance. Although all women in this study had English as a first language, some women with a hearing impairment considered sign language to be their first language. The women who experienced mental health difficulties reported receiving little or no information on mental health problems, and were of the view that health care practitioners were contributing to the silence around mental health problems during pregnancy and early motherhood. The findings indicate that ineffective communication was a significant concern for women and frequently had a negative impact on their experience of care.

The inflexibility of services and access to a range of models of care meant that consultant-led services were often unable to respond to women's particular communication needs throughout pregnancy and in early motherhood. Women highlighted the challenges encountered when

attempting to make clinic appointments for themselves and their baby and attending antenatal education classes. These women indicated a need to have access to a text service to make appointments, extra consultation time with health professionals if lip reading without an interpreter, and access to individually focused antenatal education classes. These findings are similar to those of the National Disability Survey in Ireland, which found that, although 50% of people with a hearing disability had no difficulty communicating with health professionals, 10% reported that they were unable to communicate with them at all, and 37% had moderate difficulty communicating (Central Statistics Office, 2008).

Although some staff were very skilled in responding to women with a hearing impairment and used non-verbal gestures to be understood, others were less aware of the need for face-to-face positioning in front of the woman when speaking, and spoke while walking away or from behind theatre masks. Often a third party was involved in the communication process; for example, for those encounters that included the use of sign language interpreters. These may often have been family, friends or professional sign language interpreters, which caused the women some concern regarding confidentiality of their consultation. A minority of deaf women encountered great challenges when trying to get the health service providers to arrange a sign language interpreter; they met with resistance in doing so and often were advised that they would have to incur the cost of the interpreter. In addition, women expressed concern about the third party's expertise in communicating medical information accurately, and subsequent misinterpretation of the information, which might impinge on the woman's ability to make informed choices. The Irish Translators' and Interpreters' Association (ITIA) have a code of ethics to guide the practice of professional translators while providing services (ITIA, 2009), which may offer some protection to women and ameliorate their concerns.

Specific practical difficulties for women with a visual impairment emerged. These included confirmation of pregnancy (reading the pregnancy test strip), seeing the

fetal ultrasound and making up formula feeds. Although these seem like irresolvable situations they need to be considered by carers when planning supportive care for expectant women, mothers and children. Similar findings regarding access to the environment and practical resources within maternity and related services have been reported by Thomas and Curtis (1997). McFarlene (2004) reports the difficulties women with a visual impairment experience within the health care setting. Women in this study required written information to be translated into Braille, or to have access to an audio resource, which was not available in any of the services.

The majority of women with a sensory impairment described how the interaction, communication and interpersonal skills of health professionals were impeded by a lack of awareness and sensitivity around their impairment. As a consequence women felt ignored and detached from the situation, which had a negative impact on their experience of becoming a mother. The HSE (2005) review of maternity care services in the Eastern Region suggests that women should exercise increasingly their right to be involved in 'decision making' about how and where they would like to give birth (p13). A weakness identified in this study was that, for some women, this standard was not achieved.

Similar issues arose for women with an intellectual disability who expressed their dissatisfaction when health professionals did not communicate with them directly, but rather with an advocate or family member. A strength noted was that some staff, particularly midwives, were perceived to have been more woman-centred in their approach.

5.4. Women-centred care

The findings from this study indicate the need to focus on women with a disability at an individual level within the services provided. During pregnancy and the early newborn period, women are in contact with a range of services, both statutory and voluntary within the acute and community sector. Each of these services has a

responsibility for the quality of care delivered to expectant women, mothers and babies and adherence to the legislation related to disability and equality.

Within this study, many women described experiences reflective of a focus on service provision rather than on a women-centred approach to care, which highlighted a weakness in the services. Women expressed concerns regarding the appropriateness of their care and issues related to informed consent. Some women recalled encounters with caregivers that were insensitive, inappropriate, stigmatising and discriminatory (as well as others that demonstrated empathy and sensitivity to their needs). This is potentially due to a lack of familiarity with the woman's specific needs related to her disability or impairment.

In relation to those with mental health difficulties, women reported that there was a lack of understanding around their distress. Consequently, these women described encounters with healthcare professionals that were insensitive, unsupportive and lacked empathy. Midwives, in particular, needed to create a supportive space for women to talk about their distress. In addition, women reported communication failures in providing verbal or written information on mental health issues and pregnancy. As continuity of care was not routine, women found that they had to repeat their history to a range of health professionals over the course of time. A potential solution may be to have a central electronic data record information system that can be accessed by all relevant health professionals involved in providing care. Major strengths reported were the existence of specialist mental health services for women in 2 maternity hospitals, the community mental health support group in one other area, individual therapy and a strong support system by community mental health nurses.

Many complex issues surround disability, and those with a disability face many barriers including 'separation and segregation, stereotyping, labelling and stigma' (RCN, 2007:4). Although some women reported strengths in terms of positive interactions with midwives and other health professionals that were characterised by being treated in a respectful and dignified manner, others reported less positive

experiences. These negative interactions with staff may be reflective of a stereotypically negative view of disability. Thomas and Curtis (1997) also found similar instances of disempowering practices that can result in “serious undermining of disabled women’s confidence and belief in their abilities to be ‘good’ mothers” (p209). Promoting equality for women with disabilities will involve significant efforts to overcome these barriers. The women in this study wished to be treated in the same way as any other woman becoming a mother and for them, maintaining a sense of normality rather than disability was important. Women also reported that some professionals focused on the impact of the woman’s disability on the child, and relative risks associated with inheritance, which was described by women as unhelpful and inappropriate. Women with physical disability, sensory impairment, a mental health issue or an intellectual disability felt their capacity to become a mother and care for their child was frequently questioned by health professionals. For example, some women with a physical disability reported that health professionals were more intent on dissuading them and their partner to forego pregnancy rather than to support them in becoming parents.

A weakness identified by this study was the sense of stigma expressed, particularly by women with mental health issues as they spoke of the lack of understanding that health professionals had of their distress. This left women feeling vulnerable and many described feeling that they were constantly under surveillance. This on occasion led to women feeling isolated and frustrated. The feeling of being observed and watched as they cared for their child was not reported by all women but the fear of losing custody of their baby was very real for women with mental health issues or intellectual disability. Two women with an intellectual disability reported actual surveillance and observation of their interactions with their baby by professionals. This practice may be influenced by the focus on child protection legislation in Ireland, which places a significant responsibility on all health professionals to identify children at risk (Department of Health and Children, 2004). Mothers with disabilities also felt that they were expected to achieve parenting skills as demonstrated by other mothers, without receiving sufficient support. Women with a sensory impairment also felt disempowered when professionals

communicated inappropriately, for example by referring to them in the third person. These stigmatising practices need to be addressed by providing education programmes for relevant staff.

Women-centredness reflects the principle of people-centredness in the National Health Strategy (Department of Health and Children, 2001). The interdisciplinary team providing maternity care to women comprises a wide range of professionals in order to deliver quality care for women. Birth rates in Ireland are increasing and, when combined with a current moratorium on recruitment of staff to the public sector, the challenges to plan and deliver effective care cannot be underestimated. Women rightly expect to be offered choices in the model of maternity care offered, to have access to continuity of carer, and to have access to information in order to participate in effective decision making when care is being planned and delivered. Within each unit a focus on human resources and workforce planning, and training needs analysis, is of paramount importance if the service is to become more responsive to the expectations of women with disabilities.

Quality improvement mechanisms ‘must be inherent in the development of maternity services’ (HSE, 2005:17). It is therefore essential that the structure, process and outcomes of services be developed and evaluated for all women including those with a disability. The HSE (2005) review of maternity services in the Eastern Region makes significant recommendations regarding the strategic and local planning and delivery of maternity services, and indicators of good practice are suggested. Similar recommendations to improve and modernise service configuration and models of care are made in the KPMG (2008) report on publicly funded maternity services in the Greater Dublin Area (GDA). Adoption of the model recommended within the report “will promote greater integration of both acute and community, paediatric and maternity services across the GDA” (KPMG, 2008: 223). This report makes further recommendations to include a review of current clinical governance arrangements, service re-design and the development of clinical care pathways as part of quality improvement. A framework for collaborative practice

that is both women-centred and evidence-based for women accessing maternity services, including those with a disability, should be implemented.

5.5. The need for flexible maternity care

It is crucially important that maternity services are also sufficiently flexible to meet women's needs whilst ensuring the safety of both mother and baby during pregnancy, childbirth and early motherhood. In Ireland, the National Health Strategy (Department of Health and Children, 2001) proposes that the future development of maternity services should be based on the principles of access, equity, accountability, safety and women-centredness (p2). The findings indicate a weakness in that these principles were not achieved for all women who took part in this study, and there is therefore a need to develop and improve Irish maternity services. Future initiatives should involve offering more options in relation to the model of care available to women than are currently provided. For example, the implementation of community based models of care such as DOMINO schemes (KPMG, 2008) and midwifery-led units, as recommended by two recent reports (KPMG, 2008; Begley et al, 2009c), would facilitate the delivery of more women-centred maternity services, including offering care in the home. For such changes to occur, the Maternal and Infant Care Scheme and private health insurance stipulations that underpin current maternity care service provision should be revised to include the midwife as a lead clinician in the provision of care.

5.6. The need for integrated, collaborative services

Weaknesses identified by the women in this study indicated that a fragmented approach to care is common across the country. Women's experiences reflect the absence of a planned, individualised approach to care resulting in difficulties accessing services, receiving appropriate and timely information from professionals and a lack of support in the community following the birth of their baby. In order to address this situation, an effective model of interdisciplinary referral across a range of providers within maternity, specialist and community services is required. The

HSE (2005) review offers recommendations on the use of information technology that should be prioritised to improve communication between maternity care staff, specialist services, GPs and others. Evidence from the study suggests that when a breakdown in communication occurred amongst health professionals, there was an obvious impact on women's experiences of care. Some women recalled being offered considerable support in the community by the public health nurse, which was identified as a strength of the services; however, on many occasions these promises remained unfulfilled leaving some women feeling powerless and unsupported. Consequently, referral pathways not only need to be evidence-based but require sufficient resources if services are to be delivered in an effective, reliable and timely manner.

There is also a need to establish functional relationships and close working partnerships between statutory and voluntary agencies to ensure women have easy access to services. Within this study, women did access voluntary agencies for support whether from their own action or by referral from a health professional, but this was on an *ad hoc* basis. It is suggested that best practice models for service provision for women with a disability could be based on international frameworks developed for other groups such as for children with a disability. Such models include the allocation of a key worker and the development of recognised care pathways specific to the individual from the point of identification of need.

5.7. The need for education of health professionals

In order to meet the specific needs and expectations of women with a disability, secure funding must be allocated for adequate education of staff. Supports must be made available to ensure staff can address competently and professionally the issues related to working with women with a disability. This will enable the implementation of best practice guidelines designed to meet individual needs, keeping the focus of care that is women-centred rather than service-driven. Deficits in communication between service providers and women with a disability identified as a weakness in this study suggest that there is a need for resources for service

providers to have access to appropriate education relating to issues of disability awareness, rights and equality. Examples of insensitive encounters include situations where women in labour were not provided with appropriate information in order to give consent for care. In addition, women with a visual impairment, when written consent was required, were often bypassed and consent was sought from and provided by a proxy. For women with an intellectual disability, informed consent to interventions was not sought directly and consistently by midwives when providing care during labour and during early motherhood, but was sought from a third party. Staff awareness of the legal and professional issues around consent that arise in caring for women with disability thus needs to be developed.

6. Summary

The findings from this study demonstrate that women's experiences of the publicly-funded maternity services are varied, with weaknesses and strengths identified. Some situations did occur in which the service received was suboptimal and did not meet women's expectations and needs. These findings are supported by the data from the focus group interviews with health professionals, who indicated their awareness of deficits in service provision, which caused them concern. Health professionals proposed measures to address the deficits and to enhance service provision, which should be considered actively when planning services for women with a disability in the future. Midwives within the focus groups highlighted a deficit in their knowledge and expertise in caring for women with mental health issues, which may be resolved by further education. Having identified issues common to women with disability, focus group participants also reported issues that related directly to the specific disability experienced. Women with a physical disability raised issues relating to the environment and the impact of the disability on their ability to remain independent while pregnant. Women with mental health issues reported difficulties in accessing services, a reluctance of staff to discuss any issues relating to mental health including antenatal or postnatal depression, anxiety, or psychosis and stated that they received inconsistent advice regarding medications in pregnancy and in the newborn period.

Women with sensory impairments identified difficulties in terms of the availability of written information in an appropriate format, and in the use of interpreters, with consequent reliance on others for the exchange of information. Women with an intellectual disability seemed to receive more support through the involvement of social and support workers, although HSE community childcare service personnel's perceived concerns regarding child safety and custody were raised by these women and their support workers. Despite the infrastructural and interpersonal communication issues reported, many women identified positive encounters with individual staff members in the hospital and community, demonstrating strengths in the services.

Service providers acknowledged service deficits, and the need for change and expressed a willingness to change. Similar knowledge deficiencies and the willingness for staff to be involved in change were also identified in the KPMG (2008) report.

The process of developing a women-centred service for women with disability within maternity care is complex. Changes in service delivery will necessitate extensive consultation across the professions, and interprofessional education may be a way forward. The development of any educational programme must be based on a collaborative model of interprofessional working, to include active involvement of service users/families and the voluntary sector if services are to support the true integration of women with a disability.

Factors influencing the experiences of women with disabilities include strategic, local and interpersonal issues related to the predominant configuration of the maternity services within the acute sector to the detriment of the development of support within primary care. The issues raised by women in this study are not unique to women in Ireland and support similar findings in international studies. Discriminatory practices may be based on "our society's normative assumption that disabled women are fundamentally *dependent*" (Thomas and Curtis 1997: 208) and that without the support of

non-disabled people they are rendered relatively helpless. The help that is offered is often inappropriate, and access to timely, effective, reliable assistance is problematic. Within Ireland the legislation aimed to protect people with disability, and the principles, need to be fully enacted in clinical practice. Discriminatory practices, as identified within this study, had a significant effect on the physical, psychological and social wellbeing of the women as they became mothers. Legislation prohibits discrimination on the grounds of disability, and women with disability should be supported to become a mother in the same way as other women. For many women in this study, retaining a sense of normality was a key objective. Future service developments must therefore be underpinned by a philosophy of normality and include stakeholder involvement.

7. Recommendations

From these findings the following recommendations are made:

7.1. For the Department of Justice, Equality and Law Reform

It is recommended that:

- Section 5 of the Criminal Law (Sexual Offences) Act 1993 be amended, as a matter of urgency, to enable the decriminalising of sexual relationships between adults who have capacity to consent.

7.2. For the Department of Health and Children

It is recommended that:

- A national review of maternity services in Ireland be undertaken urgently, focussing specifically on the development of an integrated care pathway to ensure that women with disabilities have full and equitable access to services that meet their individualised needs, in line with current equality, anti-discrimination and disability legislation

- A coherent inter-agency approach to service planning and delivery within and between maternity, disability and other relevant services is developed based on international best practice
- A collaborative care electronic record system, which should include the capture of specific data relating to women with disabilities, should be introduced to ensure continuity of care across HSE boundaries
- A review of the current funding arrangements within the Maternal and Infant Care Scheme should be conducted to facilitate the funding of a greater choice of maternity care models for all women in Ireland

7.3. For the Health Service Executive (and partner agencies)

It is recommended that:

- Specific national data regarding women with disability during pregnancy and early motherhood are collected as part of ongoing perinatal and disability databases
- Services for women with disability are incorporated fully into all service development plans, clinical protocols and practice guidelines within primary, secondary and tertiary care with immediate effect
- A coherent and comprehensive national infrastructure to support all new mothers with disabilities and their family is planned, implemented and evaluated, to include the introduction of a national midwifery disability advisor
- Current community midwifery services should be developed further to meet the specific needs of women with disabilities, and subsequently evaluated for effectiveness
- Within the intellectual disability sector the specific service requirements of women with intellectual disability who become pregnant are addressed
- Community mental health services be developed further to ensure that women who experience mental health problems during

pregnancy or early motherhood are adequately supported in the community

- Current expenditure within the maternity, mental health and intellectual disability care sectors should be reviewed in terms of its effectiveness in meeting the needs of women with disabilities, and these needs should be given priority in funding allocation
- Liaison and collaboration with the voluntary and social welfare sector should be developed to support an integrated care pathway designed to meet women's individual needs
- Interprofessional communication structures within and across service providers be developed to ensure continuity of individualised care
- Formalised structures should be created to facilitate service user involvement at all levels of service planning.

7.4. For maternity hospitals/units (including community care)

It is recommended that:

- Interprofessional guidelines and protocols related to the provision of maternity services to women with a disability should be developed, in conjunction with service user representatives, to provide guidance on supports required by women with disabilities, accessible premises, how to communicate etc.
- Disability awareness education should be provided for all relevant staff
- Structural adaptations be undertaken to improve the accessibility of maternity services, including the provision of more single accessible rooms to meet the diverse range of health needs of women with disabilities
- Equipment needed to provide individualised care for women with disabilities be resourced by maternity care providers immediately

- Current *ad hoc* liaison mechanisms between the maternity services and other specialist and social services and voluntary agencies be formalised to support an integrated care pathway designed to meet women's individual needs
- Needs of women with disabilities are assessed at the first point of contact and individualised care pathways are planned, implemented and evaluated throughout in conjunction with each woman
- The provision and use of third parties, including translators should be reviewed and resourced appropriately to reduce the issue of fragmented care
- Appropriate communication and information resources are developed in a range of accessible formats such as Braille, or audio resources
- Models of care that facilitate continuity of carer and increased care in the community, such as midwifery-led care or DOMINO schemes, should be implemented nationally
- Current maternity records be adapted with immediate effect in order to identify clear information on specific needs for women with a disability and the interventions required to meet these needs
- Cost neutral changes to ensure quality care within current maternity services are implemented as soon as possible to include:
 - Flexibility in appointments/location
 - Information for all women on mental health issues
 - Adequate consultation times allocated for individual assessment of needs to be undertaken.

7.5. For professional bodies

It is recommended that:

- Specific post-registration educational programmes for all staff working with women with disability be developed in conjunction with service providers, training providers and service users
- Equality and diversity training (human rights) and disability issues be included in all curricular guidelines and standards in professional undergraduate and postgraduate programmes in midwifery, nursing, medical and allied health professional education
- The needs of women who experience mental health problems during pregnancy and early motherhood be included in all curricular guidelines and standards in professional undergraduate and postgraduate programmes in midwifery, nursing, medical and allied health professional education
- Interprofessional evidence-based guidelines for the care of women with a disability be developed and implemented as a matter of urgency
- The National Council for the Professional Development of Nursing and Midwifery support the creation and development of innovative specialist posts at Clinical Midwife Specialist or Advanced Midwife Practitioner level to support women with disability.

7.6. For voluntary agencies and support groups

It is recommended that:

- Peer support groups become more involved in seeking services required at a local and national level

- Networks between current support services/groups are established to strengthen the service users' input
- Support groups seek training and funding to enhance their members' participation as advocates for service users and involvement in professional education programmes and service planning. As was suggested during the course of this research, agencies should explore the potential of establishing a 'big sister' type mentoring programme to support women with disabilities through the antenatal and early motherhood period
- Agencies create, fund and evaluate the development of centralised information resources funded by voluntary and statutory services. Examples of current good practices include
 - A parent-to-parent 24 hour helpline
 - HSE website 'Your service, Your Say'.
- Voluntary and statutory providers of intellectual disability services undertake an audit to estimate the prevalence of pregnancy amongst women with intellectual disabilities and to identify the issues that pregnancy presents for such services.

7.7. For women with disabilities

It is recommended that:

- Women with disabilities seek active involvement in achieving representation through groups such as the Irish Patients' Association, The Irish Advocacy Network, National Service Users' Executive, and Inclusion Ireland
- Women with disabilities make known their preferences for care within maternity services to inform service provision and future development

- Women with disabilities as service users become involved actively in the development, delivery and evaluation of all support services across the health care sectors
- Women with disabilities consider liaising with local voluntary agencies to seek a platform to ensure that their voices are heard.

7.8. Further research

It is recommended that further research be undertaken within Ireland to:

- Explore health inequalities further within maternity services, and their consequences for the wellbeing and quality of life of women with a disability, and for the child and family
- Investigate effective mechanisms of reducing discriminatory attitudes towards women with disabilities, and supporting service user involvement in service planning and delivery, to improve equity for women within the service
- Explore the experiences of partners, significant others and other family members in supporting women with disabilities through the maternity period.

Chapter 1 Findings from interviews with women: demographic information

1.1. Introduction

Seventy-eight women recounted their experiences of accessing health services during pregnancy, childbirth and early motherhood, 20 in the mental health strand, 18 each in the physical disability, hearing impairment, vision impairment groups and 4 in the intellectual disability strand of the study. A total of 81 face-to-face interviews were conducted (Table 1). One woman in the mental health strand was interviewed 3 times, the first interview during pregnancy, the second in the immediate postnatal period and the third interview was during early motherhood. One woman in the intellectual disability strand was interviewed twice; the first interview was during the early postnatal period and the second in early motherhood (Table 1).

Table 1 Number of interviews in each strand

Disability Strand	Pregnancy	Up to 6 Months	Up to 2yrs
Physical Disability	4	7	7
Hearing Impairment	5	6	7
Vision Impairment	5	7	6
**Mental Health	6	7	9
*Intellectual Disability	0	3	2
Total	20	30	31

**One woman in the mental health strand was interviewed 3 times

* One woman in the intellectual disability strand was interviewed twice

1.2. Participant demographics

1.2.1. Profile of all women in the study

The women's age range was 19-42 years (Mean 31.65 years, SD 4.85) (Figure 1, Table 2). Sixty-one women (78%) were married, 12 (15%) women were single and 5 (7%) were cohabiting. All of the women had support either from their partner or from family, and none were homeless. Three of the 4 women with an intellectual disability were living in supported accommodation. The majority of women (51% n=40) described their occupation as skilled, (23% n=18) as a homemaker, (14% n=11) as professionals, (5% n=4) as semi-skilled, (4% n=3) unemployed and (3% n=2) as students (Figure 2, Table 3). Three of the 4 women with an intellectual disability were living in supported accommodation.

Figure 1 Age profile of all women participating in the study

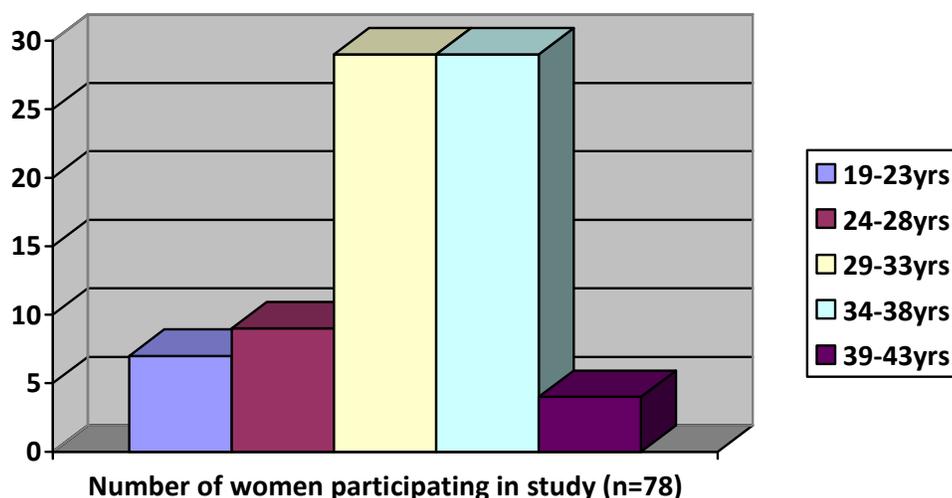


Table 2 Age profile of all women participating in the study

Age Profile	Number of Women
19-13yrs	7
24-28yrs	9
29-33yrs	29
34-38yrs	29
39-44yrs	4
Total	n=78

Figure 2 Women's occupation

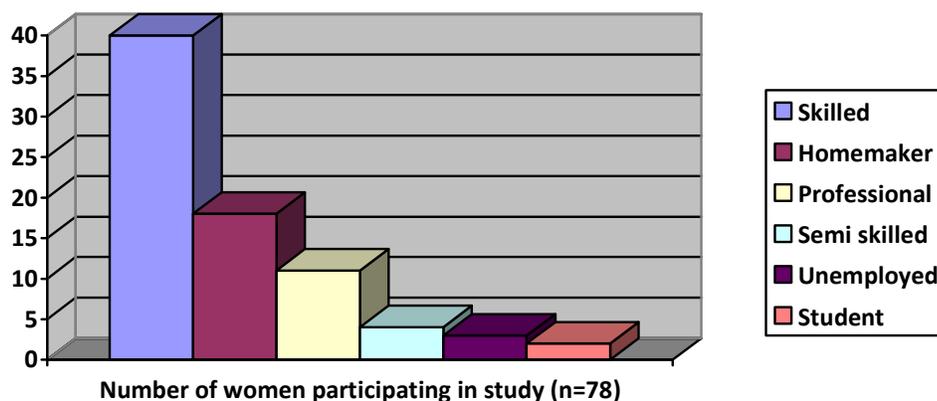


Table 3 Women's occupation

Employment Status	Number of Women
Skilled	40
Homemaker	18
Professional	11
Semi skilled	4
Unemployed	3
Student	2
Total	n=78

Over half (55%, n=43) of the women discussed their experiences during their second or subsequent pregnancies and 35 (45%) recounted their experiences during their first pregnancy. Twenty (25%) of the interviews were conducted during pregnancy, 30 (37%) during the immediate postnatal period and the remaining 31 (38%) in early motherhood.

Forty-five women (58%) lived in the Leinster region (29 of them (37%) in Dublin), 13 (17%) lived in Munster, 10 (13%) in Connacht and 10 (13%) in Ulster (Figure 3, Table 4). The majority (n=49, 63%) of women lived in an urban area and 29 (37%) in a rural location.

Figure 3 Number of women participating per region

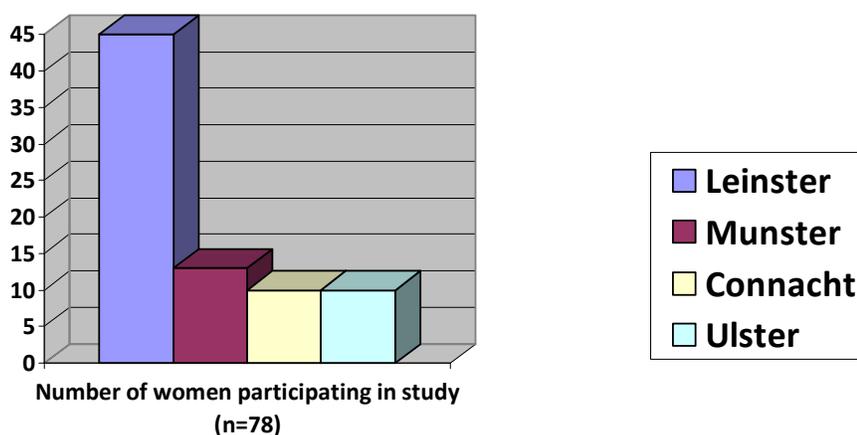


Table 4 Number of women participating per region

Disability Strand	Leinster	Munster	Connacht	Ulster
Physical Disability	14	3	1	0
Hearing Impairment	11	2	3	2
Vision Impairment	5	8	2	3
Mental Health	14	0	1	5
Intellectual Disability	1	0	0	3
Total n=78 (100%)	n=45 (58%)	n=13 (17%)	n=10 (13%)	n=10 (13%)

The largest number of women (n=29, 37%) lived in Dublin, 10 in Donegal, 6 in Limerick, 5 each in Galway, Kildare and Meath. The remaining 18 women lived in Louth, Sligo, Waterford, Cork, Kerry, Carlow, Laois, Mayo, Westmeath or Wexford. Table 5 provides an overview of all demographic details.

1.2.2. Profile of women with physical disability

Eighteen women had a physical disability. The underlying causes of their disability were as follows: 6 women had a diagnosis of multiple sclerosis, 5 cerebral palsy, 2 spina bifida and 5 other causes, all of which were due to acquired disabilities (Appendix 7, Figure 4). The other causes will not be categorised further, as doing so could possibly lead to women being identified and potentially compromise their right to anonymity. For the 11 women with either multiple sclerosis or another acquired disability diagnosis the length of the duration of the disability ranged between 18 months and 12 years (mean=6.5 years). The women's age range was 20-38 years (mean= 29.66 years, SD=4.31) (Appendix 7, Figure 5). Fourteen (78%) were married and 4 women were single, all of whom were in a long term relationship. The majority of women (n=16, 89%) were employed in a skilled occupation, 1 was a homemaker and 1 was unemployed.

Half of the women discussed their experiences during their first pregnancy and the other half recounted their experience during their second or subsequent pregnancies. Four (22%) women were interviewed during pregnancy, 7 (39%) during the immediate postnatal period and the remaining 7 (39%) in early motherhood. Fourteen (78%) women resided in the Leinster region, 3 (17%) in Munster and 1 (6%) in Connacht. Twelve (67%) women resided in an urban area and 6 (33%) resided in a rural location. Seven (39%) women used aids to assist with mobility, including a wheelchair (5) and walking stick(s) (2).

Table 5 Demographic details of all women participating

Strands	Age				Occupation					Region				Marital status			Parity	
	19-24	25-30	31-36	37-42	Professional	Skilled	Semi-skilled	Home maker	Unemployed/student	U	Mu	L	C	M	C	S	First baby	Later baby
Physical	3	8	6	1	0	16	0	1	1	0	3	14	1	14	0	4	9	9
Hearing	1	3	12	2	2	11	0	5	0	2	2	11	3	16	0	2	5	13
Vision	1	5	10	2	2	10	0	4	2	3	8	5	2	15	1	2	9	9
Mental Health	1	5	10	4	7	3	2	8	0	5	0	14	1	16	4	0	10	10
Intellectual Disability	1	1	2	0	0	0	2	0	2	0	0	1	3	0	0	4	2	2
	7	22	40	9	11	40	4	18	5	10	13	45	10	61	5	12	35	43

U = Ulster, Mu = Munster, L = Leinster, C = Connacht
 M = Married, C = Co-habiting, S = Single

1.2.3. Profile of women with hearing impairment

Eighteen women had a hearing impairment. Eleven (61%) women were deaf and 7 (39%) had partial hearing. Eight (44%) women wore hearing aids. Thirteen (72%) women discussed their experiences during their first pregnancy and 5 (28%) recounted their experiences during their second or subsequent pregnancies. Five (28%) women were interviewed during pregnancy, 6 (33%) during the immediate postnatal period and the remaining 7 (39%) in early motherhood.

The women's age range was 23-39 years (mean=32.38 years, SD= 3.62) (Appendix 7, Figure 6). The majority (n=16, 89%) of women were married, 2 were single, of which 1 was in a long term relationship. The majority of women (n=11, 61%) were employed in skilled occupations, 5 (28%) were homemakers and 2 (11%) were professionals.

Eleven (61%) women resided in the Leinster region, 3 (17%) in Connacht and 2 (11%) each in Ulster and Munster. Ten (56%) women resided in an urban area and 8 (44%) in a rural location.

1.2.4. Profile of women with vision impairment

Eighteen women had a vision impairment. Eleven (61%) women were partially sighted and 7 (39%) were completely blind. Twelve (67%) women used some aids including corrective glasses (7), guide dog (3) or a stick (2). Fourteen (78%) women had a congenital disability and 4 (22%) had an acquired disability. The women's age range was 20-42 years (mean= 32.94 years, SD=5.21) (Appendix 7, Figure 7). The majority of women (n=15, 83%) were married and 56% (n=10) were employed in a skilled occupation, 4 (22%) were homemakers, 2 (11%) were students and 2 (11%) were professionals.

Half of the women discussed their experiences during their first pregnancy and the other half recounted their experiences during their second or subsequent pregnancies. Five (28%) women were interviewed during pregnancy, 7 (39%) during the immediate postnatal period and the remaining 6 (33%) in early motherhood. Eight (44%) women resided in the Munster region, 5 (28%) in Leinster, 3 (17%) in Ulster and 2 (11%) in Connacht. Fourteen (78%) resided in an urban area and 4 (22%) in a rural location.

1.2.5. Profile of women with mental health difficulties

Twenty women with mental health difficulties recounted their experiences of accessing health services during pregnancy, childbirth and early motherhood. A total of 22 interviews was conducted in this strand, as one woman was interviewed on 3 occasions, in pregnancy, in the first 6 months postpartum and in early motherhood (after 1 year). Ten women had mental health difficulties prior to becoming pregnant; of these one woman was diagnosed with depression in childhood, began using street drugs in adolescence and is now on a methadone programme. The other 9 women reported receiving a variety of medical diagnosis including psychosis, obsessive compulsive disorder (OCD), bipolar disorder, post traumatic stress disorder (PTSD) depression, depression with anxiety, anxiety and phobia.

For the 10 women with mental health difficulties prior to pregnancy, the duration of the disability ranged from 5 to 14 years. Of the 10 women who developed mental health difficulties during pregnancy or in the postnatal period the mental health difficulties ranged from 9 months to 9 years. Six of these women were given a diagnosis of postnatal depression and experienced depressive symptoms for periods varying from 22 months to 9 years. The age range was 23-40years (mean = 33.05 years, SD=4.17) (Appendix 7, Figure 8). Sixteen women were married and 4 were cohabiting. Seven described their occupation as professional, 3 as skilled, 2 semiskilled and 8 as homemaker. Ten women discussed their experiences during their first pregnancy and 10 recounted their experiences during their second or

subsequent pregnancies. Six women were interviewed during pregnancy, 9 were interviewed when their babies were under 1 year old and 7 in early motherhood. Five women received fertility treatment. Six of the women had caesarean sections. Fourteen participants lived in Leinster, 5 in Ulster and 1 in Connacht.

1.2.6. Profile of women with intellectual disability

Four women with an intellectual disability recounted their experiences of accessing health services during pregnancy, childbirth and early motherhood. A total of 5 interviews was conducted in this strand, one woman was interviewed on 2 occasions, immediately post the birth and again when the baby was 8 months old. The women's age range was 19-35 years (mean= 29 years, SD=7.6) (Appendix 7, Figure 9), and all were single. Three of the women described themselves as unemployed and one as a semi-skilled worker. Two of the women discussed their experiences during their first pregnancy and 2 recounted their experiences during their second or subsequent pregnancies. One woman was interviewed during the immediate postnatal period and all 4 in early motherhood. Three women resided in the Connacht region and one in Leinster. All were accompanied at interview by an advocate/support person. The profile of these women differs from that of the other groupings, with higher rates of unemployment and single status.

1.3. Overall sample profile

With reference to Table 5, it can be seen that, in general, the women with intellectual disability were younger, were unmarried and had a higher rate of unemployment than women from the other strands, although the numbers are too small for any meaningful comparison. In comparison with national statistics, the women taking part were the same average age (31.65 years compared with 31.1 years nationally), and the same parity (45% having their first baby compared with 42% nationally). Occupation was harder to compare

as definitions differed. However, the rates of home-makers (25% in the study sample and 24% nationally), semi-skilled (5% compared with 3%) and unemployed (4% compared with 3%), were similar. A higher proportion were single (15% compared with a national rate of 32%) (Economic and Social Research Institute (ESRI), 2009).

1.4. Layout of findings from individual interviews

Findings that emerged from the semi-structured interviews with all women are presented in the next 5 chapters, under the 5 themes identified in the literature review as defining access to services – availability, accessibility, accommodation, acceptability and attitudes, and affordability. Results from the focus groups with health care professionals are presented in chapter 7 and the discussion, conclusion and recommendations follow in the next chapter.

The women's words are used to illustrate the themes and categories identified. Words inserted in brackets thus [], are the researchers' additions to increase clarity. Words omitted from a direct transcript are indicated by 3 ellipses thus (...). Identifiers are included after each quotation; (M13) indicates the thirteenth woman to take part in the mental health strand and similarly "P" indicates the physical disability strand, "V" visual impairment, "H" hearing impairment and "ID" intellectual disability. One quotation is included from a woman with a mental health difficulty who took part in the pilot study, because her story contributed an important aspect to the whole picture.

Chapter 2 Findings from interviews with women

Theme One: Availability

2.1. Introduction

In this theme, the extent and type of services available to address the women's needs during pregnancy, childbirth and early motherhood are described. Availability of services is discussed under the headings: structure of publicly-funded services; choice in relation to model of maternity care; availability of speciality support for women experiencing mental health difficulties; collaboration with, and referral to, other health professionals and to voluntary agencies and community services.

2.2. Structure of publicly-funded health services

When describing the extent and types of service available, it was clear that some women did not realise that if any complications arose during their pregnancy they needed to attend a maternity unit rather than a general hospital. Unaware of what procedure to follow, one woman with a physical disability was bleeding and presented late at night to the nearest general hospital but was informed that this was not the correct course of action.

'I went to the first hospital that was nearest, I went into [name of general hospital] and a nurse there actually, for want of a better word gave out to me, saying 'Well, this isn't a maternity hospital and you should have went to [maternity unit]'. (P7)

Future plans for the development of the maternity services in Ireland include the siting of some of the major maternity hospitals with general hospitals, which would improve this situation.

2.3. Choice in relation to model of maternity care

Once the pregnancy was confirmed, women were booked into the publicly-funded maternity services. Some had the opportunity to choose between different models of care. However, geographic location influenced whether or not this choice was available to all women.

'I said I would prefer to have a kind of a midwife-led service rather than a medical kind of service, or rather than a doctor, an obstetrician type service ... they said we fell out of the catchment area for a midwife-led service so that wasn't an option'. (V8)

Two women, one with a physical disability and one with a vision impairment chose to have a home birth. For the woman with the physical disability it was an alternative option to the medicalised model of care available in the maternity unit/hospital.

'I wanted to have a home birth because ... my view on the medical management had been marred and I had so many bad experiences from being in hospital and being made feel not very cared for in the whole medical thing. So I wanted a home birth'. (P10)

For the woman with a vision impairment, having the birth in her own surroundings would, she believed, minimise the anxiety, stress and vulnerability generated when navigating the new environment of the maternity unit/hospital:

'I didn't want to go to a big hospital because people come in and out, especially if it was a big ward, ... you can't actually relax because you don't know who anyone is, you feel very, very vulnerable as a blind person, it could be anyone coming in, you can't see if someone is wearing a uniform or not or see their ID cards or anything like that, they could be taking my baby... it's a ...very, very stressful environment for a blind person. So the reasons why I wanted a home birth were very, very much because I'm blind, as well as who I am and my own personality'. (V8)

However, arranging a homebirth proved challenging for both these women:

'I rang the midwife ... but she just laughed at me, she said 'No we're way too busy.' I wonder was it because I had [type of disability]'". (P10)

'[My] GP said that if I went down the route of getting an independent midwife she would have nothing more to do with it [pregnancy], because her concern was that if something went wrong the independent midwives don't have the back up of the hospital'. (V8)

When this woman and her partner met with the independent midwives they perceived that the midwives had an anti-establishment attitude, which did not inspire the woman's confidence in them.

'We got 2 independent midwives to come to the house and my husband really, really didn't like those, they were very much anti-establishment and he kind of felt that they were saying why they wouldn't work in hospitals and why they didn't want to have anything to do with hospitals rather than why homebirth was so good'. (V8)

Abandoning her wishes to have a home birth, the woman entered the hospital-based maternity services and felt aggrieved with the care received. Her wish was to have midwifery-led care, which is based on the philosophy of a holistic approach and on the principle that the midwife is the expert and lead professional in low risk pregnancy, childbirth and early motherhood, who works in partnership with women. So the woman decided to meet with the obstetrician to discuss her opinions but the obstetrician refused to see her, so she had no choice but to opt for consultant-led care.

'I kind of felt that I was kind of shoehorned into the service and I don't think it was necessarily the most appropriate service. I think that I would probably have got on a lot better with a midwife and I think that a midwife ... would probably have more of a holistic approach, more of a human approach ... and the midwife is experienced or an expert in normal pregnancy whereas an obstetrician is kind of more expert in problems and I didn't want to go down the problem route'. (V8)

The experiences described above are probably common among women, as there are very few midwifery-led services available in Ireland and few independent midwives available to provide home births. However, these women, specifically because of their particular disabilities, wanted and felt

they needed the more individual attention that midwifery-led services would have provided. The women interviewed also felt their choices were curtailed during childbirth because of their disability. They became resigned to the fact that some aspirations such as walking around in early labour, or using a birthing ball, were not options available to them.

'They [midwives] didn't give me the option of walking around, they didn't give me the option to have a shower even or a birthing ball or anything like that... I think they [midwives] were afraid of me kind of moving once everything had gone into full swing'. (P7)

'I've just become resigned that facilities and options [in childbirth] are just not there'. (V7)

One woman who had experienced mental health difficulties during her pregnancy believed that the choice of how her baby would be born was made for her.

'It was a surreal experience, you know. In the end it was a planned caesarean, and again that was something I felt I didn't have any choice in. I was kind of told, 'Well, you're having a caesarean''. (M5)

Another woman, also from the mental health strand, who had experienced childhood sexual abuse requested not to have any males present during labour and childbirth. Unfortunately, the only way the service could ensure this would happen was if her labour was induced. Another woman with mental health difficulties highlighted the difference between public and private care, in terms of choices available:

'The first time, I was in public...the nurses² have so many to look after they don't have time for you. My husband had medical insurance so we went semi-private this time ... there was only 6 of us in the room, so the nurses had more time for you. So, when I was getting upset the nurse or midwife sat with me in the middle of the night, and I was roaring and crying and ... she helped me and reassured me that everything would be ok. And she took the baby for a few hours to let me have a sleep'. (M6)

² Many of the women used "nurses" as a generic term that covered both nursing and midwifery staff

2.4. Availability of speciality support for women experiencing mental health difficulties

The services available to women with mental health difficulties depended in part on geographical location, women's knowledge of services and if they were already known to the mental health services (with pre-existing mental health difficulties). In one area women had access within the maternity services to a specialist mental health service and this was experienced by the women as very positive.

'Yeah, the midwife, she was just asking how was I, did I suffer from anything? And I told them [about mental health difficulties] ... and bang, straight away they rang up [name support midwife], said she would see me, just tell her to ring, and you'll get an appointment within 2 days'. (M8)

The importance of being able to access a specialist mental health service within maternity care that was responsive is highlighted by the following quotes.

'You're never left waiting more than a week, which is very, very good and very, very important, it's just, yeah, it was a saving grace, because I don't know what state of mind I'd be in now if I hadn't'. (M8)

'I was off medication while I was trying to become pregnant and for the first 12 weeks into the pregnancy... I found it extremely hard and I was very, very low and very anxious ... I have a 5 year old daughter and I found it very hard to cope with her needs and my husband's and my own. And I just wanted to stay in bed all the time ...so at 12 weeks I went to my GP who put me back on my medication and referred me to the [specialist maternity service] and they took it from there'. (M6)

For other women, support came from the mental health service that they were attending or had previously attended.

'So in fairness to the services in [name of mental health service] they knew me so well by then, the nurses would keep in touch and see how I was getting on'. (M16)

'I had been seeing them [mental health services] for a few years so when I got pregnant I went to see them ... and she [psychiatrist] asked me how I felt about being on the medication and I said I'd like to come off it. So gradually I was weaned off it, I went back every month, I got offered counselling, so I got counselling, cognitive, I found that a good help'. (M3)

'The mental health services were very, very good because they saw me every week...a psychiatric nurse call out to the house, which was very good because I wasn't on medication they had to keep a closer eye on me really'. (M18)

However, the vast majority of women experiencing mental health difficulties in this study reported feeling very unsupported throughout pregnancy, childbirth and early motherhood.

'I kind of felt ..., 'Oh well I can't deal with you so, you know, we'll send you to this person''. (M7)

'I was kind of very depressed and I was kind of down all the time and crying and I just went to my own GP and he just put me on a tablet and that was it...just on a tablet'. (MH11)

This lack of service provision was exacerbated for one woman who was receiving treatment for a previous addiction to street drugs. Prior to becoming pregnant she was attending a specialist service that was over 150 miles away from her home. Once she became pregnant she was transferred to a doctor 50 miles from home but again had to travel for appointments. This woman ideally would have liked support from a GP close to her home. She describes her experiences as follows;

'They're (GPs) scared about what it's going to bring, they think you're going to rob 'em or stab 'em or something like that, that sort of thing. You're going to have lots of drug users coming to the surgery...there's a stereotypical view of what drug users are like... you're supposed to be trying to live a normal life and get back into society and rehabilitate but they seem to be making it harder for you'. (M19)

At the booking visit she informed the maternity health care provider about her treatment programme but they *'didn't say much about it'*. (M19). She also found it difficult to get information on pain relief during labour. She did not

wish to have any opiates because of the possible cumulative effects of pain relief and her drug treatment on her baby, and was very concerned about the possibility of her baby having withdrawal symptoms post birth. The following sums up her thoughts on this.

'There's no service out there... like someone who knows about it [addiction]. It would be nice to talk to someone who knows about it and can give me some information and just put my mind at ease a bit more... they've left me in the lurch'. (M19)

2.5. Collaboration and referral to other health professionals

Evidence of some inter-professional collaboration and referral emerged from the interviews.

'The [midwife]... got a physio [physiotherapist] to come up and meet with me and like just run through how to do things like how to pick her [baby] up and put her in my arms like'. (P1)

'The social worker [was involved]... during my pregnancy'. (ID2)

'She [public health nurse] ... put me in touch with a counsellor'. (M7)

Some women were more persistent than others when securing a referral, which was necessary if services were to be supplied without cost.

'I actually had to argue for it [referral to physiotherapist], I couldn't walk at all. It was my mum who had to argue with them [doctors and midwives] and I got it eventually. They kept saying there's nobody here and then eventually ...they sent us up to the physiotherapist in the hospital'. (H7)

Social workers were instrumental in organising aids to assist in the parenting skills and/or alternative methods of support while the woman was in hospital.

'I have a social worker in the hospital. She got onto the child care social worker, to get care for my eldest son. He would have to go into foster care for a few days. I've no family near me'. (V4)

'I contacted the social worker, I asked her since I was going to be formula feeding was there some kind of device that I could use to help me measure water into a bottle; there isn't'. (V5)

'My social worker was ringing all over the place [to arrange supported accommodation] because she's part of the [name of voluntary intellectual disability service provider], she actually had another place in mind but the problem was it was too damp and it was too cold'. (ID1)

Some obstetricians consulted with their ophthalmic colleagues when deciding on the most appropriate care and mode of delivery.

'He [obstetrician], wrote to my eye consultant, and my eye surgeon wrote back and he said... he wouldn't advise that I would go through a natural delivery, he would encourage a caesarean section, to avoid any undue pressure on the retina'. (V9)

In one geographic location women were referred by their GP to a mental health resource centre within the psychiatric service, which offered a range of services, such as individual counselling, group work and community support, for women who experienced postnatal problems. The feedback from women about this service was very positive. In the women's views it offered a very empathetic, flexible and empowering service. However, this service was not available in all locations.

'Ach, they were just amazing, I know for a fact I would not be here today if it wasn't for [name of mental health resource centre...if I was desperate, desperate, I just knew that I had support and then ... [name of centre] always came out to visit me at the weekends, they never let me have a day without support at all. It was unbelievable and ... they would stay as long as you wanted at the house, they'd stay'. (M14)

2.6. Collaboration and referral to voluntary organisations and agencies

Despite evidence that there was inter-professional collaboration, there was little evidence to suggest that health professionals collaborated with voluntary organisations or agencies, or provided information to women on voluntary or

peer support services during pregnancy or in the postnatal period. This meant that these very valuable services were not available to all women.

'No, no none [contact with voluntary agencies]'. (P6)

'They never mentioned it [contact with voluntary agencies] at all'. (H9)

'They [maternity unit] didn't give me any alarms or anything like that, I would just ask deaf people, who have been through the experience themselves and where do you get the technology, what do you need ...and they would tell me the NAD [National Association for Deaf People, now called DeafHear]'. (H11)

'No they wouldn't have [contact with voluntary agencies] that was the impression that I got, that they're kind of completely separate institutions'. (V13)

'Nothing, no information [about voluntary organisation or agency], it would have been nice if there was'. (H2)

Only one woman from the mental health strand mentioned being given information about voluntary support services. This woman was given information on a telephone support service, which she found invaluable, during a period of extreme distress.

'They've got a phone support service in the middle of the night. I got a mobile number and if I'm in crisis ... I got very upset one night and I rang them. I just had a little chat and calmed myself down and on I plodded. But I find that service brilliant. But I get angry when I think of the fact that the HSE don't advertise that. The public health nurse told me about that. It's not advertised anywhere; it's just something they [HSE] keep in the back of their minds for somebody that's in real difficulty'. (M16)

2.7. Community support

In recent times, there has been an increase in community-based midwifery-led care provision in the form of DOMINO³ schemes, Early Transfer Home

³ "Domino" stands for DOMiciliary IN and Out. Women with no risk factors receive antenatal care in the community from a team of midwives, one of whom visits the woman in her own home in early labour, assists her through labour and escorts her to hospital in time for the birth. The woman and her baby may then go home again 6 hours later, if there are no complications, and they are visited by one of the team midwives daily for 5-7 days in the

(ETH) schemes⁴, community antenatal and postnatal clinics and 2 midwifery-led units. However, for women not accessing these specific services, there is no publicly-funded community midwifery service in Ireland, but public health nurses do visit all mothers at least once in the early postnatal period. Although a number of health professionals promised some women that they would receive extra postnatal support in the community, this was not always forthcoming:

‘When I brought baby home and the public health nurse she came the first and second day and I explained that I was visually impaired and she said ‘Oh that’s grand, I come and check on people in your situation’. God, I thought, this was brilliant. I didn’t see sight or sound of the public health nurse after that’’. (V3)

Support services were offered to one woman, (who has a 10 year history of depression and 3 children under the age of 7 years) but this promise was not followed through.

‘They offered me a great support apparently (laugh). I was to go to the day hospital in [name] for 2 or 3 days a week and they were going to arrange all that and they were sending up all the paper work, now this was back in March and I still haven’t heard from them. I haven’t even had an appointment in the outpatient’s clinic, my key worker hasn’t called, you know, it’s literally just like, they just said ‘Right that’s it’’. (M7)

For a minority of women, the availability of a community-based model of care was a structure that made their early postnatal experience very positive. These experiences were sourced either through paying a home birth midwife or accessing services in Northern Ireland by staying with a relative resident there. These quotes are included to highlight a service that is lacking, even though they relate to privately-funded schemes.

postnatal period. These schemes are only available in a small number of areas at the time of this report.

⁴ Many of the larger hospitals have Early Transfer Home schemes. Women who have had normal, uncomplicated births are discharged home with their babies within the first 12-24 hours. They are visited by one of the ETH team midwives daily for an agreed number of days in the postnatal period.

'The midwife who I'd been seeing for the home birth came to see me [in woman's own home] every day and she was fantastic, she'd stay for maybe an hour and checked that everything was fine'. (P11)

'Once I got home things did normalise a lot because I still had the [home birth] midwife come to me maybe twice a week or even more often for the remaining 4 or 5 weeks'. (P3)

'Well after I had the child I went to my mother's and they [community-based midwives in Northern Ireland] came out to see me for 10 days'. (V11)

The support offered to women with mental health problems varied depending on the individual public health nurse (PHN).

'I think she [PHN] understood what was wrong and she, she visited me quite a lot, you know, she would have come fairly regularly, especially with my second baby because she knew what I'd gone through with the first baby'. (M12)

'She [PHN] was quite good actually... like she didn't do anything in particular but she just kind of, I just kind of felt like I was getting support from her and that she was, you know she used to say to me 'Sure ring me anytime' you know 'and if you want me to call out I'll call out''. (M7)

However, this was not the case for all women; when one woman from the mental health strand described to her PHN how depressed, isolated and lonely she felt, there was no response from her.

'It was like, 'Don't give me any problems, I just want to weigh the baby and get out.'... So that's my experience on it, she knew I was suffering with depression and she never did a damn thing for me, if I was in a bad way I could have harmed my baby, God forbid, I wasn't, you know, or I could have harmed myself, and she was fully aware how I was feeling and did nothing about it, absolutely nothing about it''. (M1)

This particular woman was able to access the specialist service at the maternity hospital and received telephone support from the support midwife there.

'And apart from being able to give [name support midwife] a call I think I would have lost my reason, you know'. (M1)

In this case perceptions of lack of confidentiality and powerlessness were also mentioned.

'I think out in the country you really are isolated, you know, and the service is not good... there's one little clinic and there's a couple of public health nurses ... if you complain about one the next one that's gonna come out is going to be very bitter towards you because... everybody is discussed and your confidentiality is definitely not looked after'. (M1)

The PHN went to assess another woman because of the possibility of postnatal depression, but only visited once and did not go back for a follow up visit.

'And she [PHN] said 'Ah well I won't stay long when you're going out. 'Ah' she said 'that's a great sign altogether, that you're leaving, that you can get out of the house.'... if I don't present something like are in the textbooks, I don't have it, you know, people don't seem to realize that people have different signs... I was in that bad a state... it scares me sometimes because I don't remember the first 5 months of my son's life and I've beaten up myself so badly about it, it was awful. And the one person that was sent out to help me ignored me'. (M13)

2.8. Conclusion

In the theme 'availability' the extent and type of services available to address the women's needs during the antenatal and postnatal periods are described. In the main, services were available, but geographic location strongly influenced whether women had the opportunity to choose between different models of care. Midwifery-led models of care that were particularly suitable for some of these women were not provided in all locations.

The support services available to women with mental health difficulties also depended in part on geographical location. In one area women had access within the maternity services to a specialist mental health service and this was experienced by the women as very positive. However, for the vast majority of women with mental health problems availability of support within the maternity

services was poor and structures were uncoordinated. There was some evidence of interprofessional collaboration and a willingness to refer to allied health professionals and mental health services.

There was minimal evidence of collaboration with voluntary organisations or agencies, with very few women being given information on voluntary or peer support services during pregnancy or in the postnatal period. The community support available to women in the postnatal period was fragmented, and strongly depended on the personality of the individual public health nurse as opposed to an assessment of the woman's individual needs in relation to evidence-based standards.

Chapter 3 Findings from interviews with women

Theme Two: Accessibility

3.1. Introduction

This topic covers barriers to diagnosis, issues around accessing services due to transport, distance, or problems in making appointments; whether buildings and facilities are physically accessible; access to information in appropriate formats; and access to support services such as mental health supports.

3.2. Barriers to diagnosing pregnancy

Some women indicated that there was a delay in diagnosing their pregnancy and accessing maternity services, possibly because some health professionals tended to consider that the possibility of a pregnancy was remote.

'My local GP was actually treating me for gastro-enteritis and didn't think to ask was I pregnant or look for a urine sample or anything like that... so it was just by accident I kind of went in and said to myself well I'll take the pregnancy test and I'll see what happens and it came out positive then'. (P7)

Barriers to diagnosis of pregnancy emerged when women with a vision impairment were unable to see the indicator on the pregnancy test kit. They resorted to asking friends, acquaintances and partners to confirm the results for them, which in one case removed the spontaneity and surprise element of breaking the news to her partner and others.

'I bought a pregnancy test and ideally what I would have liked to do was do the test myself and then maybe take him [partner] out to dinner and tell him that it was positive. But I couldn't do that because my sight... I felt a bit, ah here I go again, I have to depend on somebody else and I wasn't telling anyone in the office, I didn't want to tell my

family. ...so... he's reading the leaflet and going 'Is it plus or is it minus?' and I'm like 'I don't know.', I was getting all apprehensive and he's reading it and going 'I don't know, hang on, hang on.' and he read it and he goes 'No definitely you're pregnant.' and I went 'Jesus'. (V4)

For 2 women with an intellectual disability it was the social worker or a friend, not the woman, who noticed the signs of pregnancy and purchased a pregnancy kit which confirmed the pregnancy.

'A lot of people had noticed I had put on weight and my social worker bought me a pregnancy test and she said I was pregnant and I didn't believe it and then she brought me to the hospital and they did another test and they said, I think I was 4 weeks pregnant'. (ID1)

'Well I went up to my friend and she took the test, the pregnancy test and that's how I found out I was pregnant then, with my friend...I told my boyfriend. He rang me and I told him that I was pregnant and he said, 'That's good.' I was very happy ... I was glad'. (ID2)

3.3. Information in accessible formats

Correspondence with health professionals was generally in either verbal or written format or both, which made access problematic for women with a sensory impairment. Many health professionals appeared not to realise that sign language, not English or Irish, is the first language of people with a hearing impairment. 'Normal' correspondence would thus not necessarily be easily understood:

'The correspondence to the hospital was always by letter but I would open the letter and I wouldn't understand it so... we would bring the letter with us at our next appointment and the interpreter would translate it for us'. (H12)

Some GPs offered alternative, accessible forms of correspondence and this helped to restore the women's sense of independence.

'If I visit the doctor or the GP I use the fax, but I very rarely use mobile texting, mostly I use the fax'. (H8)

'It's grand his (GP) nurse faxes me back'. (V14)

But generally alternative, accessible means of correspondence were rarely available.

'For 9 months of the pregnancy I didn't have any interpreter, it was just writing notes back and forth. I mean the doctor did try to tell me what was going on, but, you don't have an interpreter when you're with your GP'. (H1)

The issue of using a third party to correspond with health professionals and how this impacted on the right to confidentiality and privacy was also discussed.

'I got a letter that said, you need an appointment for a fetal assessment in gynae ward and I said 'What's that, what's gynae?', I never heard that word before...and you have to agree and I thought, 'Oh dear, I don't know what I'm agreeing to here.' so I got someone to ring for me, which means again, your privacy is completely compromised'. (H1)

'It's a bit of a pain you can't do it [read the information] and then things aren't confidential'. (V14)

3.4. Transport to and from maternity units

Accessibility to the maternity units was more difficult for women with a physical or sensory impairment who could not drive independently. Many relied on public transport or taxis when travelling to and from maternity services during pregnancy. Depending on the woman's geographic location and the availability of suitably adapted public transport, access to health care facilities was severely impacted upon for most, but not all, women.

'Getting taxis to go into town early in the morning is very difficult, not a lot of them will go in because a) they will get caught in traffic and b) they won't get a run to bring them out again. Buses ... were quite difficult, with schedules and things; I often missed appointments, early appointments due to traffic and different things like that'. (P7)

'I just got a taxi and if I wanted to walk I could find my way there [maternity unit] myself and that was really useful and really important for me'. (V8)

'I can't drive. Getting in and out and all of that was complicated'. (V10)

It appears that women with a disability may have several factors that lead them to be doubly disadvantaged when accessing maternity services as some of the women interviewed were single mothers, living in poverty, for whom paying taxi fares was a significant cost. Many of them lived in rural areas, poorly supplied by bus services. For one woman with a physical disability and expecting twins, driving to and from the hospital for various appointments, which were not synchronised, was *'very difficult and tiring'* (P17). For some of the women in the vision impaired strand, public transport services were inaccessible mainly because of their inability to see the bus and the inappropriate provision or scheduling of services:

'I did lobby for a bus, there is now a bus on my road, and there's a bus service which comes every half hour and goes back out every half hour, which is fantastic, but there's one problem - you have to be able to see the bus to flag it down'. (V3)

Many of the women were dependent on others, mainly partners, to transport them to the maternity units. Although the majority of women acknowledged that their partner wanted to be part of the experience, it necessitated them taking time off work. This may have resulted in annual leave being reduced thus impacting on the amount of support available to the woman when she went home after birth.

For the small number of women in the intellectual disability strand of the study, access to GP, social services and maternity unit were not viewed as problematic as all were local to them and they were supported by their houseparent to access the services.

'[The houseparent] brought me all the time'. (ID1)

'[The houseparent] took me to the GP and [the hospital]'. (ID2)

A number of health and social care professionals displayed flexibility and visited the woman in her supported accommodation site.

'He [social worker] came out here [to supported accommodation house] to me'. (ID2)

One woman, who used a wheelchair, lived close to the maternity unit so it was agreed that all antenatal assessments would be conducted in the hospital rather than alternating GP and hospital as prescribed in the Mother and Infant Scheme. Some health professionals recognised the difficulties some of the women experienced in gaining access to treatment so they would call to the woman's own home.

'Our GP, he knows I'm visually impaired... he's the only doctor that would actually come to the house to us, if any kids were sick, anything he'll come straight out. But obviously the night that he's not on there isn't a hope of getting another doctor out to us'. (V6)

Getting to the maternity units and antenatal appointments was not the only difficulty experienced. For many women, accessing antenatal classes was also complex because of the physical structures, the location of the classes or whether a sign language interpreter was present or not.

'I couldn't go to antenatal classes because I couldn't drive and it was too far away, they didn't suit me so I never went to none of the classes at all'. (V11)

'The midwifery manager wrote down on a piece of paper 'Why don't you go to the classes?' ... I said 'Yeah well there is a problem about me getting access. Like would you be willing to pay for an interpreter, provide the interpreter?' and she said 'Oh gosh no, we haven't talked about that. You have to pay for an interpreter''. (H11)

Getting to the local health centre and developmental clinics was a barrier experienced by some women with a physical and sensory impairment during early motherhood.

'The public health nurse said well you should come up to [name of local health centre] but again transport is a problem'. (P7)

'We've no health centre, we've to go to [name of rural town] and that's 70 miles away'. (V6)

The public health nurses (PHNs) in some areas were aware of these difficulties and implemented measures to ameliorate them.

'She [PHN] actually came out to the house. I wanted to do things like massage classes with the baby, I wanted to go to a mother and baby group ... but instead they got somebody from family support down to me and I had a one-on-one'. (H5)

'I suppose she [PHN] was good in that we didn't have to be going down to [the health centre] ... because ...the parking there is just crap, you know, for getting the little man out of ... his car seat, you just didn't have room to get yourself out of the car... so she was good, she came up and weighed him and that'. (P10)

For one woman in the vision impairment strand, attending some clinics was impossible. She gave the example of her 3-year old child⁵ who was unable to avail of speech therapy sessions due to this problem:

'I can't, I've no way of getting to [name of rural town], it's 70 miles away, to get a bus to town... no problem, go to the health centre, do the speech therapy, but the bus coming back doesn't go from the health centre, it goes a half a mile down the road and it's a requested stop, so you have to put your hand out, I can't see the bus coming, so he doesn't get his speech therapy'. (V6)

3.5. Making appointments

Women from the sensory strands of the study indicated that it was difficult to make appointments during pregnancy. They were reliant and dependent on others, especially family members to contact and correspond with the maternity unit. The majority of women were contacted by telephone or in written format.

⁵ This woman was included in the study because of a subsequent birth that met the entry criteria, but in interview did refer back to her experiences with all her children

'It would have been nice to have a phone number that you can text so if I need to make appointments for the hospital.... I have to rely on [husband's name] for phone calls and that takes away a little bit of my independence and I want to be able to deal with a lot of things myself'. (H2)

'I would tell my sister who has normal hearing to ring for me'. (H8)

'My mum did [ring] once, which I wasn't comfortable with'. (H6)

Appointments scheduled early in the day were not easy to keep, due to the length of time it took to get organised in the morning and the difficulties noted above with transport. Those who tried to re-arrange a time that was more realistic and workable for them were sometimes met with inflexibility and a lack of sensitivity.

'I was kind of confronted with phone calls saying 'Well, why haven't you turned up and what is going on here and you've missed this appointment again, we can't keep re-scheduling?', that was the kind of attitude now no matter how many times you try and tell them look it is difficult to get in, you kind of met with a blank wall'. (P7)

'I got a letter for the injections [immunisation programme for newborn] ... it was my GP I had to go for that and of course they only work 9.30 to 5.30, and the nurse only does the injections on certain days. So my husband ended up taking half days again to get the injections'. (V3)

'I phoned ... said 'Look I'm really sorry but we missed the appointment. Can I have another appointment?'. she [administrative staff in health centre] was like 'No, no, no we can't do that, there's not enough doctors.' and I said 'Look I'm really sorry, I'm blind, I couldn't read the letter, it wasn't in a format that I can access.' ... 'Okay well we'll definitely organise another one.' and I've heard nothing since'. (V8)

3.6. Structural environment

3.6.1. Accessing the appointment

When women attended for antenatal appointments, the mechanism of calling them for their consultation was not suitable for those with sensory

impairments. Women with a hearing impairment found it difficult to hear or determine when their name was being called.

'When we're sitting in a waiting room, we have our eyes on the person coming around and we lip read our own name'. (H1)

'...so a couple of times I missed him [doctor] calling my name because he would open the door, stand in the door way and call my name, he wouldn't actually come out and look around the waiting room and call my name. I'd have to ask the person beside me, 'What name did he call?', 'Oh yeah that's me.' and then I'd jump up'. (H2)

'I said to the woman [person at reception]... 'I want you to remember that I am deaf, so I want you to make sure that I get called in sequence, that I do get called, because it is going to be difficult for me, I won't hear my name". (H11)

'Mixed up, confusion, over here, over there... they'd say 'Sit over there.', then you'd sit over there, you have no information on what's happening, where you are in the queue, are you going to have to wait ... you don't hear your name being called, somebody taps you and says 'That's you.', ... and you go up and somebody ... says 'Go here.' or 'Go there.' or 'Do whatever.' and you do that and then they say 'Sit down again', so you sit down, you kind of just live from moment to moment and you're sitting in the hall'. (H10)

Women with a vision impairment found it hard to locate a seat or determine which room the health professionals were in, and this was more difficult for them if they were unaccompanied. This experience was not unique to the maternity units but was also experienced in the paediatric hospitals. However, for the women in the study, it was not an issue in the GP surgeries or community-based models of care.

'... [In] the waiting room you had to find a seat and to be honest without help, without sight assistance I would have found all this traumatic, extremely traumatic'. (V4)

'... [A] big room...for a blind person that's really hard, it's like 'Take a seat.', 'Where?', all I can hear is this big massive room and I have no idea where the seats were'. (V8)

The time spent waiting to be called in for their consultation was more difficult for people with sensory impairments, as those with sight impairments could

not read magazines while waiting and those with hearing impairments were afraid to read for fear of missing their names being called.

'I would never read a magazine, deaf people can never read a magazine in a waiting room like hearing people'. (H1)

'I can't pass away the time the same way others might, others could sit there and read a book or do a crossword or something, I was just sitting there, I suppose that just makes the time go longer'. (V14)

Some of the midwives were sensitive to the difficulties women may experience and did intervene to minimise the effect.

'When I did go to the [antenatal] clinic the nurses knew me and knew I was deaf and they would walk over to me and say 'now' and indicate it was my turn'. (H9)

'They [midwives] were actually quite nice, there was no, no horrible bad attitude at any time, they came to the door when they were calling you in there was no overhead beeper or anything'. (H6)

Some women, particularly those with a sensory or intellectual impairment, considered the time allocated to antenatal appointments too short, which prevented access to effective exchange of information.

'I always felt that they [doctors] rushed through it but it's probably just the normal in out, in out, but I actually stopped him and I said 'Look, I'm deaf. Can you just give me an extra 5 minutes? I'd be grateful because I need to lip read.' ... I didn't feel he was giving me 100% of what I was expecting of him'. (H2)

'[I] thought they [doctors in maternity unit] were going too quick'. (ID2)

For women experiencing mental health difficulties attending appointments was challenging sometimes because of previous negative experience within the maternity services.

'...I had a fear going into the hospital [for appointments] because I had been in to have [name] and I had all this work done [talking about previous traumatic birth] so I thought it was going to be the same again'. (M11)

For others the impact of the mental health problem on self-esteem left women anxious and vulnerable about attending. This was exacerbated by the apparent lack of any structured appointment system or the presence of a friendly face to help women navigate the system.

'...[Be]cause I was explaining how hard it was even to go in for the appointment, that you know I wasn't even sure if I was going to make it in that day'. (M9)

'Going public you're waiting a long time, you could be 2 hours waiting before you're seen'. (M12)

'...Its just dog eat dog in there, there's no system, there's nobody telling you where you should be sitting or it's just mental in there, you know, people could be left sitting for hours and hours and then realise that they didn't report to the right nurses or knock on the right door'. (M1)

This woman goes on to describe an incident where someone jumps the queue and takes her place while she is waiting to see a member of the team involved in specialist maternal mental health service.

'So I'd to sit another hour and I went to the reception and I thought, I said 'That girl's after skipping the queue. She's after taking my appointment.', but anyway when I did get into him [psychiatrist] I wasn't fit for anything, to talk to him or anything, but that was the bedlam in that department...it doesn't do any pregnant women any good, because you're there too long, far too long, you know, for anything to be of any benefit to you'. (M1)

Some local health centres and paediatric hospitals were inaccessible for women with a sensory impairment.

'I hate the centre [local health centre], you go in, everybody is staring at you and you say who you are and who your baby's name is and they'll [PHNs] say 'one minute' and then they'll call you over here, and you don't know what's going to happen'. (H10)

'At [name of paediatric hospital] ...it's only when I look around and notice nobody else is moving. I had to ask someone next to me 'Did they say [baby's name]?' and they said 'Yes you're right.' and then I go in'. (H5)

Some clinics outside of the maternity and paediatric services were not easily accessible to women with young children and their equipment. This, coupled with lack of child care facilities meant that this woman with mental health difficulties was unable to attend the psychiatrist and had not, 6 months later, been sent another appointment.

'And I did get an appointment for the outpatient clinic but I couldn't make it because I'd no one to take the kids and the place that I have to go is tiny and it's like a long narrow corridor where everybody sits and you just can't bring small children into it, can't get a buggy into it even. And I rang and I said 'Look I've no one to mind the kids. I'm not going to be able to make it.' and she just said 'Ah right that's fine.', that would have been the end of April and I haven't heard from them since'. (M7)

3.6.2. Physical layout of clinics and wards

The design of the built environment was a key determinant of accessibility and impacted significantly on women in all strands of the study. Gaining access to the physical environment was a major challenge encountered by these women. For some, parking was an issue:

'Parking, I had to park in the disabled spot up the road at the [area on main street] and walk down to the hospital, there was high humidity that day and high humidity makes my [disability] worse and I had to walk up and back, it was the only parking space available'. (P17)

'Parking in the [name of maternity unit] is a nightmare and there is a designated space but it's not policed and inevitably people park where they shouldn't'. (P5)

The women interviewed were complimentary of some recently constructed maternity units.

'The whole hospital was wheelchair friendly'. (P12)

'There's a ramp, there's an automatic door so it senses the wheelchair coming to the door, which is great'. (P13)

For others, even gaining access through the front doors was difficult:

'Not all the entrance doors are ... automated, so that's difficult ... you're trying to balance yourself and try and get the door open... I had a number of appointments for early scans ... and that had a couple of steps down to it... my husband got me up and down in the wheelchair. So he basically pulled me and the chair up and down it. I was annoyed, I thought in this day and age there's no need for that and even if people had to get buggies up and down, it wasn't just me ...'. (P5)

'The hospital is extremely inaccessible ...for people who are visually impaired or blind, the stairs are badly marked, the rooms and the signage is very bad, so I would always rely on [husband] going somewhere, going for a scan or whatever. Even all the signs up on the walls, which are important signs...you miss all of that when you're visually impaired'. (V9)

'They have shoved the maternity section out into an outbuilding ... and it's really, it's not nice at all. You kind of go up a ramp so you do, and this is inside the building, but there's a big set of very big steps when you come back, when you're coming back out of the consultant's room, they're very steep and some of them are not even marked'. (V12)

Once access was gained the challenges continued with the units' interior structures. Health care facilities and physicians' offices were difficult to access for the majority of women with a physical or sensory disability. Women described the environment as cold and unwelcoming, negotiated and navigated only with the assistance of others, mainly family members and occasionally health professionals.

'I would have to ask [for assistance], even though I had my fiancé with me I still had to ask. They [midwives] were good enough to help me, there was no, there was no objections not to help me'. (V4)

'I'd have to have one of the porters push me down [to the antenatal clinic]'. (P13)

'... My husband was with me ... the obstetrician actually had become really quite aware so that was the only time and he actually guided me to the seat which was great'. (V8)

'I'm not dependent by nature, but because when I go back into the maternity, it's unfamiliar territory again, I have to go dependent on someone'. (V9)

Women rarely attended the maternity unit alone.

*'[The houseparent] had taken me to all my hospital appointments'.
(ID1)*

One woman who did attend the maternity unit alone said she felt *'...very vulnerable now when I was there on my own'*. (V10). The reception area and corridors were described as unwelcoming:

'I had to talk to a woman in a booth [reception desk] and that was a nightmare because she was quite short and her mouth was covered by the opening of the booth ... I was distraught anyway, that was horrible because I just couldn't hear anything she was saying to me'. (H5)

'The narrow corridor for someone with a crutch ... some people wouldn't get out of your way and that was hard to negotiate but in hindsight [name of maternity unit] wasn't for somebody with any disabilities or with any movement problems'. (P10)

'It's a really steep ramp, and when I go down there then [antenatal clinic], it's a tight little space down there to get through, there's lots of chairs in the corridor, the main reception ...it's high, so I have to lean over to show my hand, but other than that they wouldn't see me. I wave, or I cough, I normally cough, 'Hello, I'm here''. (P13)

One woman with a physical disability was admitted to the antenatal ward during her pregnancy and found it to be very large, which posed difficulties for her when moving around.

'It was a big ward but I found it difficult to get around for the simple reason that I had no crutches with me and I had to keep asking for a wheelchair and even then there seemed to be only one on the floor and every time I turned my back somebody had taken it for somebody else to go down to the labour ward...it was kind of annoying that I had to call a nurse every time I wanted to go to the toilet'. (P5)

Using bathroom facilities independently was challenging particularly as some maternity units did not have wheelchair-accessible toilets. Arrangements were made to accommodate one wheelchair-user but these arrangements were different to those of the general population and only served to highlight the woman's disability:

'They give me a couple of bottles [to collect a urine sample] every time I leave and I bring a sample in with me. You should have the option to do what the other mums are doing, you're standing out if you don't, you're something different, you know, the other mums just do it, I'm taking mine in my bag and handing it in'. (P13)

3.6.3. Navigating around the unit

Orientation and navigation around the maternity units was difficult for women with a vision impairment. The lack of appropriate signs compounded the difficulties even further.

'Signs obviously you wouldn't read, unless you asked somebody you know they're not going to kind of go around and read all the signs for you'. (V14)

'I kind of go to the security guard at the desk and kind of ask that person and sometimes they do point to signs and I kind of go 'Well, could you just tell me' or whatever. I can read signs but I'd literally have to be up right under them and practically touching them and at that stage you kind of know where you are...'. (V2)

'I just couldn't find my way around because you've to go one place for bloods and you've to go one place to be weighed and then you've to go another place to see a doctor and ... I found it all confusing. Then I had to go downstairs for a scan, they knew I was visually impaired because it was on my file but there was never anybody offered'. (V6)

Lighting was also an issue that added to the functional nature of the building.

'The lighting is always neon, it's cold lighting ... there's always streams of people moving...queues forming here, there...numbers being called ...it just gives this impression of people being passed...it's impersonal. Once you're actually dealing with a midwife, a doctor they're very nice, but the building itself is functional and you're there for something really personal and really joyful and it just clashes with that'. (V17)

Many of the women discussed how busy and crowded the maternity units were. The volume of persons within the unit made navigating the physical environment difficult. In addition the long waiting times were exhausting and difficult to tolerate. Some found the experience traumatic and likened it to being herded like 'cattle' (V14 and V19).

'The maternity itself is a horrible building, it's just a very, very old building... it's too crowded. It's like going down into the dungeons, going down to where the scanning and all that is'. (V10)

'The clinics are not in any way shape or form set up. You have a kind of production line. You can certainly get in the door but it's not very easy, these things certainly haven't been thought of really well'. (P8)

'There was queues out the door... and I was like, oh my God, we had to get through admissions to get onto the other queue, I couldn't believe it, I could hardly stand. Eventually ... I did stay standing and got to the...check in desk and then I was just joining the next queue and there was some steps, it doesn't look like anything to most people, but I was like, oh God, oh God, I can't and there's no handrails on those steps, and there's usually a pram parked or there's somebody who won't get out of your way, and it's just, oh, it's such a nightmare, it really was'. (P10)

'So I queued ... I found that very, very stressing and the amount of people there, found the whole place, couldn't cope, too big, no sign posts and especially when nobody was expecting me and no file on me, nothing, the whole experience was horrible'. (V6)

When one woman with a physical disability was asked to retain and carry her maternity notes, a policy practised in some maternity units, she found it physically difficult.

'You had to bring your folder with you each time you were in and out, and it was like, crutch, and handbag, well, okay ... your balance is, you're kind of used to handbag and crutch but the folder as well was kind of, too much'. (P10)

3.6.4. Postnatal ward

The physical environment of some postnatal wards generated a lot of discussion. The majority of women indicated that the wards were generally inaccessible. One woman with a physical disability described her postnatal experience, as a consequence of the inaccessibility of her environment, thus:

'I just felt like oh my God I felt so, so alone and isolated like'. (P2)

One woman with a vision impairment had difficulty determining who had entered the room because people would come in unannounced. To overcome this problem her GP advised her to put a note on the door to say she was blind but the woman did not agree with this advertisement of her disability. It was difficult for women with a visual impairment to navigate large open units and communicating for women with a hearing impairment was very challenging. In contrast, in cramped, enclosed wards the space to accommodate additional equipment was limited.

'I found it very, very stressful because the wards are so big and everything is so open'. (V4)

'What I couldn't see was things like drinking water or bells or lights or getting round the bed and the ward itself where the sink was because it was very small'. (V9)

'I just hated every minute of it. It was so cramped... I actually got a corner. I got a window. So I had an extra bit of a ledge. None of the other women, they literally had bed, cot, bed, cot, bed, cot that was it. We were milled in. We were like rats in there'. (P2)

'It was the ward that they put you into after caesarean section, so I didn't get any sleep at all, so I tried to explain to them (midwives) that sleep was really, really important for somebody with [disability] and that I needed either to go home or to be given a private room'. (P3)

However, small enclosed spaces helped to ameliorate some of the acoustic challenges encountered by women with a hearing impairment.

'It was such a small enclosed area that the acoustics of the room were easy to hear what the person was saying'. (H5)

Sometimes women were allocated to an unsuitable area and, in one instance, it was the woman's partner who identified the inappropriateness of this.

'They put me into a room with 6 beds and I was in the middle on the opposite side to where the bathroom was. My partner went up and explained that was going to be awkward for me so they did switch the beds so I was next to the bathroom which made it easier'. (V14)

Women were more comfortable when they were aware of their surroundings but they were rarely orientated to their new environment.

'The notices were written up that people had to wash their hands before they held a child ... nobody said that to me. Nobody said to me that these are the lights, this is the bell, none of that was kind of relayed on to me. So you just had to find things for yourself'. (V9)

'I wanted a shower and I hadn't a clue where the showers were and the midwife said it's ... just down there, so you're kind of wandering looking for the showers and they're not signposted, toilet or shower or whatever'. (P10)

Similar experiences arose around mealtimes.

'When dinner and food were coming around, they [catering staff] were saying 'You go over there to eat.' Where is over there, like where do I [go]?, I would rather starve. I had no dog, I had no cane, when somebody would come in, I didn't know if they were talking to me or the woman next door in the next kind of curtain separating us, they are saying 'Are you alright?' and I'm going em 'Yeah.' and they weren't even talking to me at all'. (V5)

Some women with a vision impairment were conscious of the various appliances and equipment that resided in and sometimes cluttered their surroundings and environments.

'One thing that they've [household staff] an awful habit of doing, is leaving wires running across the floors, you're here feeding your baby ... they're dynamite. They're washing floors, hoovers, there's wires going across and they're the things that I do fall over, equipment being just left everywhere, that's very difficult'. (V6)

Bathroom and showering facilities in some postnatal wards were deemed to be inaccessible by the majority of women with a physical disability. Many women were unable to shower independently and some got their partner to accompany them to the shower/bathroom.

'I couldn't have a shower for the time I was there [in postnatal ward] it was not accessible'. (P2)

'I had to get [partner's name] to come into the shower with me because you have to step up into the shower. There wasn't the staff there [in postnatal ward] to accompany me into the shower. (P9)

There were no facilities to sit down or feel secure in the shower and no help was offered.

'[The] first shower I remember, you're really wobbly and all you need is a seat and handrails and when I saw the shower I was like, oh my God, there is no handrail, there is no seat, there isn't even a place to put your shower gels and stuff, you had to pick things off the floor and that's a no, no... you just can't do it, you could be on the floor quicker than you realise...getting back to bed was, it was like you're really drunk and you're just looking for a wall to fall against. So I got back and I just lay down for ages, but at no point was there any offers of help'. (P10)

'The bathrooms were very small. I had to hop off the wheelchair and kind of crawl into the bathroom on my hands and knees. The wheelchair would be just outside the bathroom'. (P12)

3.6.5. Equipment

Women encountered many challenges during pregnancy, childbirth and early motherhood when using equipment, particularly equipment that was fixed and not adjustable. Many relied on health professionals to help overcome the challenges. Some women experienced a lack of willingness, manpower and suitable equipment to help transfer them safely onto the examination couch. One woman with a physical disability even contemplated taking her own equipment with her when she went into labour.

'One of the biggest problems I had ... was having to climb up [on examination bed], I mean it's difficult enough when you are not pregnant to get from a wheelchair into something like that but, it's very often impossible. But certainly add the baby weight onto it, it's basically nuts. But yet I would have to get up and down off these things because they didn't have adjustable beds'. (P8)

'I have a special chair at home that I put into the bath and it's remote control so it lowers me up and down in the bath...and it's lightweight, so we were thinking when I go into labour to bring that up with me. You shouldn't have to bring your own stuff from your own home in'. (P13)

'They [antenatal classes] wouldn't be accessible to me because I wouldn't be able to get on mats so I wasn't offered any antenatal classes. I would have liked to have done them if I had the opportunity'. (P5)

Some equipment in the delivery suite was described as inaccessible and a hoist to aid transfer and positioning was not always available. Some delivery suites were perceived as being ill prepared for women with a physical disability.

'The only thing would have been stepping up and down on to the bed, it felt very high and I was afraid with the pain that I, just felt that I might fall off'. (P6)

For women with a hearing impairment, who could not hear the baby's heart-beat on the cardiotocography machine, the midwives and obstetricians were conscious of the need to reassure the woman about the baby's well-being. So they used non-verbal methods of communication to affirm that all was normal.

'They [midwives] turn it up [cardiotocography] so you can hear it [baby's heartbeat] and going thumbs up'. (H14)

Women recalled how the equipment was generally inaccessible in some postnatal wards. Maternal beds were inaccessible and difficult to negotiate.

'I slept most of the time in an armchair, I set it up so I could sleep in the armchair rather than the bed because it was just too difficult getting in and out of the bed'. (P5)

Sometimes bells were not functioning and a few mothers found that baby cots and incubators were too high and inaccessible. This rendered it difficult for some new mothers to lift their babies out for feeding or cuddling.

'I'm in agony and ringing the bell, my bell doesn't work I got the only bell in the place that didn't work... I'm ringing and ringing and I had to get the girl beside me to ring her bell... everyone else was getting out of the bed and they were lifting their babies and I'm... looking at my little fella in through this gold fish bowl and I'm like 'I can't get you son.'. (P2)

'The only difficulty was that the buttons [to gain entry] were too high up, I wasn't able to stretch. I would have to have someone with me all the time when I would go up to see [baby's name]...and...the incubators were high...I would have to stretch to see him'. (P12)

'I couldn't use that [baby cot]; I couldn't use it at all. To lift the baby out was far too difficult'. (P8)

'I wasn't able, there was no way I could change [name of baby] of even get her out of the little cribs, I just wasn't able to do it'. (P18)

For others the baby cots posed no issues.

'The cots were ok. They've wheels on them...so they were actually quite good'. (P7)

Some midwives did attempt to address the issue of an inaccessible baby cot, which was appreciated by the women.

'One midwife said to me there has to be something better than that cot ... and she caught something in the antenatal they screw onto the side of the bed ... It looked like a mad yoke, it was just like 2 bars and then a space right ... next of all the cot is getting closer and closer to the bed ... I was able to grab [name of baby] by the shoulders and drag him onto my bed'. (P2)

Parents sourced practical aids and equipment to facilitate parenting skills from health professionals, usually the public health nurse (PHN) and/or voluntary organisations and agencies.

'If I need anything [aids for parenting] I've gone to her [PHN] for them. I've used her [PHN] department for other aids and appliances'. (P2)

'I knew about the alarm [baby alarm for hearing impaired women] and I had to get a friend to go to the National Association for the Deaf to get a form for me to fill out, she had to bring it back to the hospital for me to fill in and then she had to bring it back to the National Association for the Deaf, they gave her the alarm and she gave it to me, it would have been nice to actually have that form in the hospital with a lot of other information'. (H2)

'I had this little silent alert thing to wake me up but...it was difficult'. (H1)

3.7. Accessing emergency services

For women in the hearing impairment strand, contacting the emergency services was very challenging, which meant that they were not freely accessible to them. They relied on friends, family or neighbours to contact the emergency services and when they did these persons were often unable to answer some of the questions posed.

'My husband translated for the paramedics'. (H12)

'We rely on a neighbour to phone, or a member of our family. The services [emergency services] don't have a text message service. My sister-in-law rang 999 and there were a few questions on the phone about the address and why and where and what was going on'. (H9)

When the emergency service personnel could communicate in an appropriate format the woman was very appreciative.

'The ambulance man could do the signing, good night and goodbye, and he was great'. (H9)

Forward planning was therefore essential.

'He [husband] found someone who was reliable and he took their number and he arranged that he would send a text message and then they would ring the ambulance'. (H12)

3.8. Accessing mental health support

Women who were attending one maternity unit where there was a specialist mental health service located on site reported very little difficulty in access, as the service appeared to be proactive in referring women and was very responsive in terms of appointments. The service involved having direct access to a support midwife with expertise in mental health and a perinatal psychiatrist. The aim of the service is to develop a strategy for the prevention, early detection and management of perinatal mental health problems and postnatal depression. This includes identifying a population at risk, facilitating

appropriate support and accessing a range of services for them. Team members also act as advocates for vulnerable and depressed women to ensure their needs are addressed, provide educational programmes for professional disciplines who provide care for this group and actively participate in research to enhance the mental health service. An information leaflet on the 'support midwife service' is given to all mothers who state that they have a history of anxiety and/or depression at their booking visit. This enables women to think about their needs and ring directly for an appointment at a time that suits them. Referrals are made by other health professionals also. Support and information is provided by telephone when appointments are not practical and specific problems need to be dealt with quickly. In the hospital, the Edinburgh Postnatal Depression Scale (EPDS) testing is offered to all mothers on day of discharge from hospital. The public health nurse and GP are informed of the score via the hospital discharge liaison sheet or by phone where necessary.

One woman, in her second pregnancy, accessed this specialist service for women with mental health difficulties. A plan to reduce possible trauma around childbirth had been agreed in partnership with the woman.

'I saw [specialist support midwife] about 2 weeks beforehand and we went over the plan [agreed plan of care] again and she said 'Yes everything should be all in order. It's on target to happen the way it's supposed to.' (M15 (2nd interview))

Another woman (M2) who had experienced postnatal traumatic stress disorder (PTSD) following the birth of her first baby was currently pregnant and was referred, at the first antenatal booking visit, to the specialist mental health services for help and support with her mental health difficulties. She had appointments with the psychiatrist and support midwife, and was given information and counselling for PTSD. As a result, the remainder of her pregnancy was enjoyable. Other women also appreciated the service and highlighted the importance of having specialist services to provide support and information on perinatal mental health issues:

'I was asked if I'd like to talk to someone so I said 'Yes.' so [name] is the midwife [support midwife]... fantastic, from the time I went to see her things got a lot easier, you know. I went to see her before the structural scan at 20 weeks and she was great, she helped me cope with what I was feeling and you know saying things that you are afraid to say'. (M5)

'I was roaring crying. I was in an awful state, thinking, I felt so bad and yet I was afraid to take medication in case it hurt the baby. And she [GP] reassured me that it wouldn't, that I needed it, and she rang the [hospital] as I sat there and asked for the support services and the [name of specialist maternity service] rang me the next day with an appointment...[Name of support midwife] she visited me in hospital every day I was in there, for a chat. She was very good yeah'. (M6)

The benefit of access to specialist care and getting support and help, either within the maternity services or postnatally within the mental health services when experiencing mental health difficulties, was considerable. This woman, commenting on the specialist service with the maternity care services, said:

'You're never left waiting more than a week, which is very, very good and very, very important, it's just, yeah, it was a saving grace, because I don't know what state of mind I'd be in now if I hadn't...for the first time I'm actually feeling back to my normal self in a long, long time. And I'm absolutely terrified I'm going to go through the whole lot again now after the birth, so, but they won't let that happen they said'. (M8)

Another woman commented on a specialist postnatal service that she was attending with a mental health service:

'She [name of mental health nurse] came once a week, maybe twice some weeks, ...I don't know where I would have been without her...honestly if I hadn't had [name] through the pregnancy I don't think I'd be here, I don't know to be honest what way I would have been, if I hadn't had [name]'. (M11)

For many women where there was no specialist mental health service within the maternity service their experience of trying to get help for their mental health difficulty was not positive. They reported difficulty in accessing support, with a sense that they were hostage to the fragmentation and lack of integration between maternity care and mental health services.

'I fell between the stools, the maternity service washed their hands and said well we're not dealing with it because it's a mental health issue, mental health were saying we're not dealing with it, she's pregnant... I mean the funny thing is, just in a nutshell, they can whip me in with the [names another physical health issue] but they can leave me out there with a severe mental health issue'. (M10)

'They [maternity services] didn't offer me anything ...as far as I was aware there wasn't anything to offer...I think they just kind of thought...ah well if you're being seen by the psychiatric services then we don't need to do anything...I mean I don't know if the maternity services do offer any sort of support'. (M7)

'I found though the maternity services didn't really tend to take into account the bi-polar, so they weren't as supportive as they could have been...on one hand you had, I suppose, over-caring from the mental health and then non-caring from the maternity, maternity was just concerned with the pregnancy and the baby'. (M18)

In the absence of specialist mental health services within the maternity services, women were left to try and seek support from GPs and mainstream mental health services. In some situations the women did receive support as highlighted by this woman:

'... When I was trying for this baby she [psychiatrist] spoke to me and she said 'As soon as you find out you've conceived you must let us know in here.' [psychiatric services] ... she reassured me that [postnatal depression and psychiatric hospital admission] is not gonna happen again and they're gonna do out some working plan or something, ... I just feel I've got the support here [mental health resource centre], I think that's why I'm not worrying. I didn't have that support the last time because I didn't know it existed'. (M14)

However, for others, support was not as forthcoming:

'No wonder people suffer because when you openly ask for help from your GP and they don't recommend things, you know it's very disappointing... I had to do my own research into alternative health, I couldn't find anything, the GPs don't recognise alternative health either. I told him I was going to a hypnotherapist when I was pregnant, just to see if it would help and he was like 'Yeah whatever' (laugh) 'away with you'. But he'd never suggest the name of a counsellor or someone to go to talk to ... I think the GPs need to maybe have a list that they can refer you on to people or the mental health service needs to advertise more, publish 'If you need help please contact us and we can arrange counselling.' and that'. (M9)

Another woman who was experiencing extreme stress and asked her GP for help recounts her experience:

'And I thought 'What's this stress doing to the baby?' and I went to the GP for help and he looked at me and he said 'I don't sleep either.' and dismissed it. He said 'You've a perfectly healthy pregnancy; I'm not prepared to give you any more support'. And I said, 'I think this is ...becoming a much more severe difficulty''. (M10)

When this woman went to the antenatal clinic to get help and support, she described her experiences as follows:

'I... went back and I said 'Look, I need some help here.', and ... I was referred to [name of psychiatric hospital] and ... basically they said 'We can't give you any medication because you're pregnant and we're just going to send you home. We'll try and get you some psychology in a week.'... but they couldn't get anything that day and I needed something that day, I was exhausted'. (M10)

Her meeting with the psychiatrist did not provide the support she needed.

'The consultant muttered something to me about 'Do you ever have bad thoughts?', and I looked at him and I said 'No, I don't have suicidal ideation, no, not at all.'... I was beginning to think at the end that maybe I should have made up something so that they would have done something'. (M10)

Because of the difficulty in accessing services this woman moved back to England for 4 months.

'We really moved lock, stock and barrel because the service was so poor and they were just refusing to understand me. I felt there was a whole stigma around the fact that I wanted medication but I was reading books that said if the woman is stressed medication should be used'. (M10)

Another woman tried to get support from her GP for mental health issues and described feeling

'Isolated and ... a little bit kind of shoved into a corner ...a little bit forgotten about really'. (M7)

She then contacted the mainstream mental health services and was commenced on medication, but no in-depth psychological support services were offered:

'They started me on the [name of medications] and I don't know, I think things had gone kind of too far at that stage for to just pick up and you know pretty much through the rest of the pregnancy like things weren't great...'. (M7)

3.9. Conclusion

In this chapter the women's experiences of accessing maternity services were presented, and illustrated a number of challenges. The main areas identified by the women related to the barriers to diagnosing pregnancy including possible misdiagnosis by professionals; the limited availability of information for some women in accessible and confidential formats; and issues with making and accessing appointments at midwifery and specialist mental health services. Structural environmental issues were also highlighted in terms of inhibiting physical layouts, navigating around units, accessing transport, utilising equipment and women with physical disability managing their own notes. For women with a hearing impairment, the emergency services were not really accessible as contacting them was very challenging. The benefit of being in the right part of the country to access specialist mental health services, and getting the necessary support and help when experiencing mental health difficulties was considerable, but was available to few women.

Chapter 4 Findings from interviews with women

Theme Three: Accommodation

4.1. Introduction

The way in which service providers gave care and organised the distribution of resources specifically to facilitate or accommodate the needs of women with a disability, when they accessed health services during pregnancy, labour, childbirth and in early motherhood, is discussed under this theme. The main areas of interest that emerged from the women's narratives included: providing information, planning and preparation, continuity of carer, assistance and support, communication with health professionals, and flexibility in policies and procedures.

4.2. Providing information

Women spoke of the aspects of pregnancy and birth where the provision of information was essential for them to comprehend what was happening. There were many examples given of good information provision, but problems were also identified.

4.2.1. The ultrasound scan

The ultrasound scan facilitates the visualisation of the baby and for many potential parents it is a mechanism of confirming the pregnancy and providing reassurance that all is well.

'I went there [to the maternity unit] about 3 weeks into the pregnancy... I had to go down to [name of city] to get a scan to see how far I was gone'. (ID3)

'As soon as I had the first scan, you just feel, you think yeah there's definitely a wee baby in there and ... you're sort of, like, have to protect what's in there'. (H4)

Unfortunately, for some women with a vision impairment, the opportunity to visualise their baby was lost due to difficulties in seeing the screen when staff did not accommodate their needs.

'The ... screen was too far away from me and it was too small and if you sat up, went up on your elbows it disrupted things and they didn't particularly want you to do that and they weren't particularly helpful either'. (V10)

'My experiences were really bad ... I couldn't see it because the screen was so small and ... the room was dark ...and [the doctor] was really shocked, 'You can't see that, the heart is beating. Look this is the hands, this is the face, yeah you can see it, you can.' He couldn't understand why I couldn't see'. (V16)

'It's only a small screen, it's totally inaccessible'. (V9)

The room and surrounding environment was dark, so for women with a hearing impairment, lip reading the sonographer was a challenge, and obtaining reassurance via the verbal word was impossible.

'The lights were off and the screen was on and I said 'Oh excuse me I'm deaf. I really need the lights on because I need to lip read you and to see everything''. (H11)

'I told her [midwife] I was deaf so she was no problem and pointed to some things then but because the room is kind of dark, she was conscious that I mightn't be able to see or hear what she was saying'. (H2)

Some women commended the sonographers on their awareness and sensitivity when trying to accommodate the woman's disability. Some took their time when scanning and explained the findings clearly and in a reassuring manner.

'The scan was brilliant, he [doctor] was ... really taking time to show me, he was going 'That's the baby's backbone and there's the kidney.'

... he did take time and he gave me a picture... I just found him very, very good'. (H4)

'They [ultrasound midwife] did say everything is alright, thumbs up, good, good, fine, fine, so at least you had some information'. (H10)

'The [ultrasound midwife] explained everything....which way he was lying and which way his features were ... they were quite good'. (V4)

'She [ultrasound midwife] allowed me to hear the heart beat so that to me made my day, made my visit'. (V5)

'They [ultrasound midwife] were good ...they were doing their job good ...looking after me and making sure I was alright and the baby was alright and putting on the scanning thing and telling me to rest myself and that kind of thing'. (ID2)

The women interviewed appreciated their efforts. Their actions and sensitivity contributed to the attachment process, which was occurring during the antenatal period.

'I wasn't able to really connect with it [baby] until that doctor just put my hand on the vibrations of the heartbeat and then I felt connected to it'. (H1)

But not all health professionals were so accommodating.

'They [sonographers] made no effort. They didn't want to know basically [about woman's impairment] and she said 'That's not my problem''. (V3)

'They [ultrasound midwife] were quite rude really'. (V10)

'I didn't like the woman that done the scan. I did tell her I was hard of hearing and I said to her 'Would you please explain things in detail?' and she wasn't a bit helpful ...it was a big deal that she had to explain to me... I could hear her sighing and huffing and puffing and I could see the expression on her face, it's like 'Oh you're bothering me.', like, and I was very upset over that'. (H13)

Obtaining reassurance was difficult.

'There was very little reassurance at any stage ... you were part of a process, when you came to the end of that process it was 'Next person.''. (H3)

'I didn't come out [from scan] reassured at all. I was referred for a more detailed scan and then I was like 'Why, or what's wrong?' or, no nothing, nothing, he [doctor] didn't explain...'. (V16)

'They [ultrasound midwife] just explain if you want them to explain, otherwise they don't say anything'. (V18)

For one woman with an anxiety disorder who went for a scan with the hope of being reassured that her baby was healthy, the experience of having repeated scans and an amniocentesis increased her distress. She also expressed the view that there was some subtle pressure surrounding consent.

'I'm 35 and I was worrying and my anxiety getting worse, you know, and the scan, the doctor saw something on the screen... As it turned out he had an enlarged nuchal... It's usually a sign of Down's syndrome so that's where we started from ... I had an amniocentesis done at 12 weeks, looking back I feel I was kind of pressurised into it ...the scan was done one day and the amnio was done the next... very quick and even the morning I was getting it done (pause) there was a tiny risk of miscarriage but you know, you need to have it done....I went along with it anyway. There was other tests done and they came back fine which was great. But then the next thing, if all the chromosomes come back okay, then it's physical disability or cardiac. So for the whole pregnancy I was having tests and tests. I didn't have a normal visit. I was always in the scan rooms...'. (M5)

Health professionals had a tendency to discuss the findings of the scan amongst themselves, with no understanding of the women's sensory loss and their resultant communication needs. The women interviewed described how they felt removed and detached from the conversation.

'They [ultrasound midwife and doctor] did it [discussed the findings of the scan] all among themselves, I was kind of on my own ... obviously this was an interesting thing and there was an army of them around the monitor all discussing the whole thing...'. (V6)

'They would all talk to each other ... I was trying to work out what [the midwife and doctor were saying], and I thought, hey, there's something

wrong here, I couldn't hear what they were saying or didn't know what was going on'. (H1)

'I just kind of resigned myself to the fact that I couldn't see it [monitor], I would like to have seen it. There was a part of me, it's my baby, I want to see that screen'. (V9)

However, the women were very reluctant to complain about the services received.

'I was so annoyed [with the service] but I never complained, I should have complained. I wouldn't have the confidence in myself to know what to say or what to do'. (H13)

For the deaf women whose first language was sign language the exchange of information was facilitated by the presence of a sign language interpreter, but concentrating on the interpreter did interrupt their visualisation of the baby's image on screen.

'The interpreter was there ... I was so engaged with what was on the screen, I just wanted to look at my baby on the screen, I didn't want to look at the signing, yes it was great and they told me that everything was healthy and fine and that was a great relief as well and that was it'. (H12)

4.2.2. Exchange of information

A proper exchange of information between women and health professionals is essential for high quality care. The failure to provide information in an appropriate or accessible format was instrumental, in some instances, in an inadequate exchange of information. This appeared to be caused primarily because of some health professionals' lack of sensitivity or knowledge of how to communicate appropriately with a woman with either a visual or hearing impairment. Consequently, women felt ill informed and reverted to seeking information from alternative sources such as the internet, family and/or friends. For those that used the internet, many used Australian or American information sites.

'Any information I got, I got myself. There was a leaflet given to me, just a leaflet on things you eat and things you don't ... [but] any information I got, I got myself. (P8)

'Most of the research on the C section in general I had to do on my own'. (V13)

'My mum has a friend and she has CP [cerebral palsy] and she had a baby, she had 4 kids now, so I kind of sat with her and asked her a few things'. (P7)

'I didn't understand it [condition of pre-eclamptic toxemia] but then I was able to go home and research it on the internet and so on and then I started to understand a little bit more about what is going on'. (H1)

'I never thought I had depression... I'd be googling depression and postnatal depression on the internet. Reading about it, and one half of me was saying 'I think that's me' and the other half was saying 'You're just imagining it. You don't get depressed. You're grand. You're just tired and bla de bla, over-emotional and over-protective.'. (M4)

One woman in the vision impaired strand contacted the National Council of the Blind:

'I rang the National Council for the Blind and I asked them for any books they had on pregnancy and ... of course I was quite apprehensive because what if this isn't the same information as what the hospital are providing, I kind of wanted to follow the rule of what the hospital were giving me'. (V5)

Some women who had had a previous mental health problem spoke of learning about their increased risk of postnatal depression from books.

'I really didn't know much about being pregnant and... I just presumed that, you know, I'd always have this depression but I never thought that it would escalate and I never thought of postnatal depression or anything like that, you know. It wasn't until I start reading books, you know, while I was pregnant ...that I realised that I am going to be more susceptible to it, you know'. (M1)

The women in the intellectual disability strand recalled being encouraged to ask for information.

'Well they'd say 'We can give you information. We can give you the help. Ask questions.', all the questions they had the answers to and I didn't feel like I needed ask them anything'. (ID1)

'I asked them [midwives for information] [but, at other times] 'No I didn't really [ask for information]. Because I thought they wanted to do their job and they were busy... They could have helped me more ... they could have sat down and explained to me a bit more''. (ID2)

'[Understanding of the midwives' questions] A little bit, not really. Not all of them. I'd ask them to talk more'. (ID4)

Where information was provided it was usually in print format, which was not always the most appropriate; this contributed to the women in the vision impaired and intellectual disability strands feeling ill-informed.

'They give me a book [with] pictures, baby pictures. How to do [look after] the baby, dress the baby... Difficult to understand. Read[ing] difficult for me. ... I ask them to teach me more'. (ID4)

'On our first visit...after my doctor sending the letter off explaining that I was visually impaired and for all information to be put into Braille, they handed me a folder...there was a whole load of information booklets, leaflets, pamphlets, the whole lot, all in print and I nearly cried, I did, there was tears coming into my eyes, there was a lump in my throat'. (V5)

'You almost feel lucky just to get it [information] now never mind any kind of format that is accessible for you'. (V7)

'They give you booklets and leaflets and stuff and I did just say 'are any of these electronically available or in large print?' and they said 'no". (V2)

'They gave me a lot of leaflets [in the antenatal period] and everything like that but I said to the nurse I found it difficult to read it...I would look at the pictures and I tried to read it'. (ID1)

Women with an intellectual disability found the use of visual teaching aids at the antenatal classes informative:

'[Antenatal classes] Good...[They] teach me how to push baby out...[using] teddy bear, doll, baby doll'. (ID4)

Some women relied on the person who accompanied them to the maternity unit to read the information for them. Frequently this person was their partner. Relying on others to read the information was, however, very frustrating for the women.

'It's frustrating [to have husband to read it] and it undermines you and it highlights the difficulties'. (V8)

'My partner said 'Look, I'll read it to you.' but I mean who wants to be sitting there with their partner going on about breast feeding and different types of labour and everything, it was something I wanted to read for myself as a woman, it wasn't going to happen to him... it's my first pregnancy like, I want to know what's going to happen to me'. (V5)

'People would be laughing at me [because she couldn't read the information] ...it bothers me sometimes...it hurts'. (ID1)

Some would take the information home but rarely referred to it.

'I didn't read any of it [written information], I just said 'Thank you.' and I took it all because you don't want to offend anyone'. (V1)

'They gave me a leaflet, a book, I didn't read it... I read one book...I didn't read that bit [what was going to happen over the next 6 months], I didn't read it, I didn't want to be fat'. (ID3)

The potential therefore for women to misunderstand the significance of the information being relayed by the health professionals was huge.

'My hands were getting swollen [woman developed pre-eclamptic toxemia] ... I remember my wedding ring that I had, and they wanted me to take it off and it was difficult to take off and I started to laugh, I wasn't being serious and the nurse gave out to me for laughing and I didn't know what was going on. She said 'We're going to have to cut your ring off.' and I was saying, 'Oh my God, what's going on, what's wrong?'. (H1)

Women with a hearing impairment remarked on the importance of having an interpreter to relay the information from the health professionals in an appropriate and understandable format. Community-based models of care

were more accommodating in meeting the specific needs of one woman with a hearing impairment.

'I really needed an interpreter in order to have that basic information, there were 3 or 4 people in ... [maternity unit] ...standing around, writing down notes, and I really, I didn't know what was going on...and I was nervous as well and when you're nervous it's harder to write English because ... it's not your first language'. (H1)

'Without an interpreter it was just writing and therefore the information was very brief'. (H19)

'They [DOMINO scheme] did leave a number and some information leaflets and said that if you had any problems whatsoever don't hesitate to ring or whatever, or text ... it was just brilliant'. (H6)

Some women felt that the exchange of information was minimal, which was disempowering.

'You are trying to grab these people [midwives and doctors] and ask these kind of questions, 'Well what is going to happen?' or 'What is going to be done?' or 'What are you doing to me?' ... it is quite frightening ... when you are being met with a blank wall, it is scary, it is quite scary'. (P7)

'I had big problems [at the first booking visit in the maternity unit]...I did not understand the information, the questions, do you smoke and go to the toilet and give a sample, I didn't really understand anything what was being said to me'. (H10)

'You don't know what is happening to you you have an alien in your belly, in your tummy and you don't know what you're supposed to do, just go with the flow and you don't know what's going to happen'. (V18)

'...my spirits were extremely low in the early stages of pregnancy and I didn't know what was wrong with me then because nobody ever said that to me, I thought when you'd fall pregnant, you know, I knew that you could be sick and stuff like that, but I didn't know that you could sink so low. Nobody ever explained that'. (M12)

One woman with a vision impairment recounted how she felt a loss of control and how the lack of clear explanation fanned this sense of loss.

'Loss of control, you're on the cold examining table and the man [obstetrician] touches your belly and okay, and listens and then says

'That's fine, thank you very much.' and you don't have a clue about where is the baby'. (V18)

While one woman with intellectual disability (ID2) praised the GP for his helpfulness, she felt that he could have provided further information.

'He [GP] told me more about my pregnancy. About when the needles were due for the baby, explained it... and explained eh...if you are feeling unwell or that come to me and, you know. And iron tablets as well. There wasn't enough... telling you things... there wasn't enough explaining I thought'. (ID2)

Family members attempted to facilitate the efficient exchange of information by acting as the women's advocate.

'My dad said to him (obstetrician) 'Can I speak with you outside?' and the doctor said 'Well I'm not going to break any confidentiality between me and my patient.' but dad said 'It's nothing to do with confidentiality, I just want to explain about her deafness ... because', he said, 'I'm listening to her getting upset and she's stressed about everything.' so he said 'Okay' ... From then on when he'd visit he'd make sure that I understood everything before he left the bed'. (H2)

Women with mental health difficulties reported receiving conflicting advice about medication, which was a major source of distress and anxiety, especially in relation to the possible effects to the fetus.

'They said they just had to check for things in the scan, to make sure that the baby was alright ...they were a bit shocked ... because the doctor ... said that I should never have been put on that medication because somebody of childbearing age shouldn't be put on it'. (M18).

Another woman recounted how she had been taken off her medication by her GP, which had a detrimental effect on her mental health.

'Yeah I didn't have my first visit till I was 19 weeks so in the meantime I had to go off the [drug] completely, I think I was 10 weeks and I started to get symptoms of the OCD [obsessive compulsive disorder] back again'. (M17)

Following referral to a specialist mental health service this woman was seen by a perinatal psychiatrist;

'He [perinatal psychiatrist] advised me to go back on to the [Names same drug] and basically weighed out what the options were, that if I was very, very stressed it's not good for the baby, or go back on a low dose of drug, it's the lesser of 2 evils'. (M17)

The lack of accommodation to these women's needs is often due to lack of knowledge on the part of maternity service staff. The importance of women having access to specialist advice is highlighted by this woman's experience:

'Well as soon as I found out I was pregnant I came off medication I was taking for panic attacks and I had my first kind of check up in the [maternity unit] at 17 weeks ... and by that stage I was suffering quite bad with the anxiety that I wasn't able to get out of the house ... So I mentioned it to the midwife when she was taking a history and she said 'Well you know there's things that we can do.' ...so they put me in touch with [name] in the [maternity unit] who was absolutely wonderful, got me in the same day and then the following day, she rang... to say [perinatal psychiatrist] had a cancellation and could I come in that afternoon and ... I found out that the medication I was on was perfectly safe, there was a mild risk in the first 12 weeks of the baby developing a hole in the heart but because I was well into 17 weeks at that stage that there was no concern. And it was one of the medications that you'd be allowed breast feed on as well... It was just so reassuring to hear that and find that something could be done'. (M9)

4.2.3. Sign language interpreters

Arranging a sign language interpreter for interacting and interfacing with the maternity unit was complex and difficult for some women in the hearing impaired strand. Women requested an interpreter that was qualified and accredited to interpret and translate medical terms; however, sometimes this proved challenging. Some women were advised that they would have to pay for the interpreter.

'It's very hard to get an interpreter. There's only one in the mid-west and you have to book them 6 weeks in advance. It's the hospital's responsibility'. (H7)

'I got a letter from [name of maternity unit] and it said you've requested an interpreter, but, we have a staff nurse here who's able to sign ... so I thought oh okay. So the first visit...she never turned up. She wasn't there. And that worried me... [eventually] I got the interpreter that I wanted but I fought very, very hard for that'. (H1)

Some contacted voluntary organisations and agencies such as DeafHear and they were instrumental in arranging an interpreter.

'My GP referred me to the hospital, DeafHear gave me an interpreter's name and I said I want [interpreter's name] to be my interpreter and we put it on the file so that was clear'. (H12)

Having an interpreter present facilitated a dignified and respectful interaction.

'The interpreter was there. I was able to have a proper dignified conversation and question and answer session. Whereas before I was just relying on trying to read their facial expressions and so on. So really I was able to ask the interpreter things like, 'What's their voice like? Has she got a soft voice or does she, does she sound strict and harsh?' and the interpreter was able to explain this to me'. (H1)

If an interpreter was not present, family members or friends were often asked to fulfil this role and to interpret for health professionals. Again the potential to misunderstand what was said was intensified.

'My father was there and he helped the chain of the communication. They [midwives and doctors] wanted [father's name] to stay overnight because if anything happened he would be ready and available to sign and communicate'. (H9)

'Sometimes, depending on who was with me, they might try and interpret but I mightn't understand their attempt to interpret so it was very hard'. (H10)

Some units acknowledged the importance of having an interpreter and did engage the services of one without being requested or prompted by the women, but it could delay visits.

'When I got to the reception of the paediatric clinic they said 'Oh you are deaf and we need to get an interpreter.' and I said 'No it's alright

you are only looking at the baby.’ They said ‘No, we can’t do it without an interpreter.’ and so I had to sit and wait until the interpreter came’. (H9)

The lack of appropriate and accessible information provided for these women was highlighted by the number who contacted one or more of the Trinity College researchers after meeting them at interview, to ask where to go for information on issues such as counselling, advice on contraception, or the existence of mother/toddler groups.

4.3. Planning and preparation

4.3.1. Antenatal classes

For many expectant parents, antenatal classes would be the common avenue of preparation but for women in this study this avenue was not always accessible to them. Many felt that their specific needs were not addressed or accommodated in the antenatal classes. A few described the classes as inflexible and unhelpful, contributing to their feelings of being unprepared and ill informed. Some women actually chose not to attend antenatal classes.

‘I was only referred to an antenatal class ... in the last 2 weeks of the pregnancy which is absolute lunacy ... So no preparation, nothing as regards labour or anything like that, nothing’. (P7)

‘They [antenatal classes] were a joke. I got nothing out of it I have to say. I wasn’t given any information’. (P2)

‘I wasn’t impressed with antenatal classes... they did a whole class on breast feeding and I found that really upsetting because I knew I wouldn’t be able to do it for long [due to MS drugs], there was no information on bottle feeding’. (P6)

‘I didn’t take them [antenatal classes], mostly because of the lack of time and I knew I probably wouldn’t be able to understand the teacher. I just felt it probably wasn’t going to be worth it’. (H7)

‘I heard about them [antenatal classes] but I didn’t go to them... [I] didn’t feel like going to them’. (ID1)

The women described the classes as too large; some found the content, strategies and aids used within the class inappropriate.

'I found that [video] really difficult to follow because obviously I couldn't hear the person talking over the video ... so I didn't really follow it 100% ... I was lost ... because there was no subtitles on them'. (H2)

'It is all geared to fully sighted people. I suppose if I went in with a white stick it's different but because you can't see my disability, they assume I don't have one'. (V6)

Women were unlikely to inform the facilitator of the classes that they had a disability or impairment.

'It was a big class I wasn't going to stand up and say 'Hi, I'm really worried about dropping the baby.' or I wasn't going to disclose that I have [type of disability]'. (P6)

However, a few women did find the antenatal classes very helpful and the strategies employed were considered appropriate.

'I found them [antenatal classes] fine, that's because I sat up beside her [facilitator] and I was in front of her'. (H13)

'She [midwife] sat in the middle and everyone was around her and ... she went around everyone then individually and asked questions ... I found her very, very good and if we had any problems, she gave us her number then and said 'Ring me if you've any worries.' I found her brilliant I must say'. (H4)

'They [midwives] were preparing me for the pregnancy and they also wanted me to talk about my worries because through my pregnancy I worried a lot'. (ID1)

Some maternity units were very aware of the women's specific needs and implemented measures to ensure that antenatal classes were accessible for women with a disability. Measures included ensuring the woman was in an optimum position to hear, engaging the services of a sign language interpreter or organising one-to-one sessions if appropriate.

'She [midwife] always used to look at me and she would kind of give me the signal, 'Do you understand?' I'd nod back to say yeah I was fine. So she was great now, she made a huge effort like and she made a point of kind of standing near me ...I found her very good'. (H13)

'I spoke to the midwife concerned and I said 'Look I'm deaf.' So she said 'If you stay up the front all the time and if you concentrate on what I'm saying, you should be able to gauge from my lips'. She said 'If you're in my line of sight I'll make sure that you can see me.'. (H2)

'I will be having one-to-one talk with the antenatal class in the next couple of weeks'. (V4)

'There was a nurse ... when we [woman and manager of supported accommodation] were going to the classes she used to talk to me one on one'. (ID1)

Women in the mental health strand reported receiving very little information on mental health issues or on how to access services should they experience a mental health problem in the antenatal classes. The women were of the view that the focus was on birth and breastfeeding with little recognition of the emotional impact of birth on women's mental health. If and when mental health issues were discussed it was mainly with reference to the 'baby blues', with little or no reference to depression during pregnancy, postnatal depression, anxiety, or psychosis.

'No there wasn't [any information on mental health]. There was a big focus on a natural birth followed by you have to breast feed or that'll be the end of the world'. (M4)

'I know I did attend a good few classes but I, it was really the exercises and the breathing... the puff and blow [class] I call them'. (M13)

'I knew that the baby blues would probably last for a day or 2 but nobody told me that this could go on for a longer length of time'. (M12)

'Not one of them mentioned postnatal depression, not one mentioned it, not one at all'. (M14)

A few women were of the view that there was a conspiracy of silence around mental health difficulties and childbirth that permeated society and maternity care.

'If they said that in the antenatal class, or if someone came into you in the maternity after you had your baby and said things mightn't be rosy...but...we don't say it to each other so why do we expect nurses to come and say it then. Nobody wants to burst anyone's bubble, when they're having their first baby that things mightn't be rosy, it might be rosy for them'. (M4)

4.3.2. Using a birth plan

When asked about preparing a birth plan many women described formulating one but the implementation was viewed with scepticism. A number of women expressed the view that a birth plan should not be done unless it is going to be carried through as they took up a lot of time, thought and discussion with family members. When the plan was then ignored, some women intimated that they felt out of control and completely disempowered.

'You got your birthing plan ... it's printed small but I filled it out... they were never adhered to so they're a waste of time'. (V6)

'I remember they [midwives] looking through the birth plan I think there was very much a sense that 'Ah, here's another one of these annoying things.' (P11)

'When I went into labour ... the birthing plan was never mentioned so we didn't take it out of my bag... I was waiting for someone to ask and they never did so I said I'm not going to be stupid and take it out'. (H4)

'They didn't really ask about the birth plan or ... did I have any plans of how I'd like the birth to go myself, and I did but I didn't want to speak up like, I didn't want them to think.... I felt like that they thought they knew best'. (M3)

'I had it [birth plan], but nobody ever asked me for one'. (M12)

Although the above comments might illustrate a common problem that all women have, the effects were particularly negative on women with a disability. For example, one woman who had experienced a previous traumatic birth and was diagnosed with posttraumatic stress disorder and phobia following the birth of her first child had carefully considered, developed

and agreed a birth plan involving a caesarean section. On the day of the birth, however, the anaesthetist decided not to follow the plan and tried to convince the women to have an epidural rather than general anaesthetic, thus causing unnecessary distress and fear for this woman:

'But there was a reason why that plan was there, it wasn't to indulge me...when she tried to get the IVs in and I was kicking and screaming, she got a notion that ...bullying me wasn't going to work and that I wasn't just looking for an easy way out...but she gave up in the end and had to put me out because I was in a terrible state'. (M15)

4.3.3. Assessment of needs

There was evidence that women in the intellectual disability strand of the study had a formal assessment of needs conducted in order to plan their care; this usually took the form of a case conference.

'They [multidisciplinary team] had a care plan meeting just before, about 2 or 3 weeks before I had [the baby] where there was a midwife, there was a whole load of people from the hospital, my social worker and [the houseparent] and my father, just talking about generally ... they basically were saying what would happen to me when I was in the hospital and if I get somebody to help me, which nobody did. They asked my social worker if she could get somebody to come in but they couldn't do it at night. So it was only the nurse [in the maternity unit] that came in and kept an eye on me'. (ID1)

In this case when the action plan was developed, however, it was not communicated to the woman until nearer the birth.

'They [health professionals in maternity unit] didn't really talk about it [a plan for when the baby was born] at the start, it was only when I was just about to have [baby], when all the meeting they were just talking about it that time'. (ID1)

Another woman in the intellectual disability strand perceived her needs around being pregnant were not being addressed during her stay as an inpatient at the local psychiatric unit.

'No ...they [nurses in psychiatric unit] were just helping with people that were mentally sick'. (ID2)

However, the majority of women with a physical disability or sensory impairment reported that there was no forward planning or assessment of needs conducted.

'No, no, none [planning] despite the fact I had brought it to their attention on numerous occasions they didn't make any attempt'. (V3)

'No, none at all, no nothing, nothing, I didn't ask either ... no nothing I think I learned to adapt to situations'. (V6)

'It was such a big, it was a life changing experience...I didn't know how I was going to be able to manage so there was no support. I would have loved somebody to come to me and say 'Okay, right, what do you need?'. (P2)

'No, no ... there was never a question of like would you need anything in particular during the delivery or after the delivery'. (P9)

'There was no systematic effort or procedure to deal with somebody with a disability, or so I thought'. (V17)

The lack of forward planning generated a lot of stress and anxiety for the women and did impinge on the birth that they had anticipated and planned for.

'I felt a bit upset that there wasn't a plan'. (V5)

'He [anaesthetist] looked at my back and went 'You are not having an epidural.' and I said 'Why?', he said 'Because we don't know where to stick the needle' [woman had spina bifida] 'and nobody has done any planning and nobody has done this or that, and we'd have to talk to your neurologist and if you want an epidural, it ain't happening today.'. (P8)

Women in the study appreciated any effort to address and accommodate their particular needs, but this was dependent on the individuals that they met.

'My patient services manager ... asked me...ideally what would I like'. (V5)

'The public health nurse called [during antenatal period] and said 'I see you are due soon. I'm the public health nurse and I know you've a

vision impairment. Is there anything at all we can do for you, just let me know.' so that was great'. (V16)

'The public health nurse contacted me [during antenatal period] ... she gave us [woman and partner] her direct number and said 'When the baby is born give me a ring and ...if you have trouble breastfeeding we can sort it all out, don't worry about it.' kind of thing, she is kind of practically competent'. (V17)

There was a lot of evidence that when women with mental health difficulties attended maternity units where there was a specialist mental health service available, their individual needs were assessed. However, in the absence of a specialist mental health service many women reported that even if the maternity services were aware of mental health problems they did not follow up or accommodate the women's needs, and left it up to the women to let them know if their mental health deteriorated.

'Well they more or less said 'Well you are attending a psychiatrist so they are looking after that.' ... we didn't discuss it in any great detail but they said 'If you are having any problems let us know.'". (M16)

'Researcher: Was that even brought up, was your mental health discussed?

M 10: No, not really.

Researcher: Or assessed?

M10: No... because the anxiety was all in the past, I told them that I'd been on [medication] in the past and that I'd had a traumatic past, but no it was never really identified as an issue, and I trundled along okay until I was about 20 weeks pregnant'. (M10)

'I found the maternity services didn't really care about me, it was all about the baby... they didn't make extra appointments, they didn't keep a watchful eye on me or anything like that, they didn't ask anything about the bi-polar or anything like that'. (M18)

4.4. Continuity of carer

Many women discussed the complexities and challenges associated with a lack of continuity of carer. Some did meet the same obstetrician but this was a local arrangement and was not the general practice. Meeting the same person

at each antenatal appointment was considered a positive person-centred experience, but it was not the norm.

'I found him [obstetrician] excellent. Going to see the same person all the time is really, really important, they can get to know me because my experience is that people tend to be a little bit, not patronising, if they don't have an experience of blind people, they might not feel comfortable, they might trip over their words or they might, not feel comfortable and just not treat me in a normal way'. (V8)

'I wasn't getting shipped from one person to another. That was brilliant like, I was just going to one person, I wasn't getting tossed and going to see different people'. (P2)

'I preferred that one-to-one and they know what is going on and you have got the continuity of the one person, the one style of lip reading and everything'. (H8)

'I would have preferred the one doctor really you know ... because you kind of, you feel relaxed and things like that because you kind of get to know them so you relax'. (ID2)

Continuity of care was facilitated by community-based models of care, which were considered user friendly and person-centred.

'The DOMINO scheme is good because then you know the people. ...you're able to call [the midwife] at any time of the day or the night and you know that there's someone who's going to listen to you and help you out to the best of their abilities, I think that was good'. (V18)

'There was no problems I found it very easy to speak to them [DOMINO midwives], very, very easy. Everything was at your ease. Everything was done in the house... They are actually a brilliant team'. (H6)

A lack of continuity of carer contributed to the challenges encountered when communicating and interacting with health professionals. Some of the women interviewed expressed frustration at having constantly to relay information about their disability or impairment to different people at each antenatal appointment while others considered it undignified.

'It was different people all the time, different nurses, there was a range of different people and you saw whoever you saw when you got there'. (H10)

'Dealing with every Tom, Dick and Harry in the hospital, I was afraid that I'd have to go explaining my case over and over all the time'. (H13)

'Every time I had a different one [midwife or doctor], so you never really get to bond with any one'. (V1)

If the woman's partner or sign language interpreter was present the challenges encountered by the lack of continuity of carer were ameliorated.

'So many different people and that's okay as long as [interpreter's name] and my husband were both there'. (H12)

4.5. Assistance and support

4.5.1. Assistance and support from health professionals

The women talked about the support they received from health professionals, that demonstrated the accommodation of the services to their needs. Partners, family members, houseparent and personal assistants were also named as key sources of physical, emotional, social and psychological support during pregnancy.

'The nurses can't do enough for you'. (P13)

'I have very a supportive family, like my mum goes everywhere with me so she helps me out a lot with things like that, all the forms, lifts to the GP, lifts to the scans'. (V16)

'I kind of depended on my mum'. (H7)

'She'd [manager in supported accommodation] be there talking to me and she'd be asking me am I alright and you know she'd sit with me'. (ID2)

'I have a PA [personal assistant] 5 mornings in the week ... only for that I'd be lost because I've no other family, my family is all in [place name] and I've nobody else here so only for the PA I would be lost'. (V11)

Women with an intellectual disability who were accessing supported accommodation described the manager in that facility in very positive terms:

'She [manager] did enough like, she was good ... she's like an angel ... because she comes in and she checks on you to see are you alright and she cares about you, she cares about people. She does ... she's the nicest woman I ever met. The nicest person I ever met. My mother said she's a lovely woman too. And ... she's there for you when you need her ... she's better than all the other ones ... she's just a nice woman...she's very caring ... different to all them other people in the hospital... she doesn't boss you around. She's not a bossy person. She'd be kind of nice to people. Making them feel comfortable'. (ID2)

Midwives were perceived as a source of strength, support, companionship and a conduit for effective communication, particularly during labour.

Continuity of carer also helped to facilitate effective communication.

'She [midwife] was a fantastic help ..., she gave me strength, she gave me courage ... she didn't frighten me or anything'. (H13)

'The nurse was staying with me and she [nurse] was lip reading and talking and talking and talking and it was great, it felt great, one-to-one... she was very nice, she was explaining everything'. (H8)

'The midwives were excellent, the one in the labour ward couldn't give me any more help than she was giving me'. (V11)

'The midwife she was nice... she sat in the room for ages talking to me...she stayed like and checked me ... she kept talking to me like and telling me what was going to happen ... she was telling me about the labour like, telling me what I'd feel like ... telling me like it might be a bit sore and she said 'Get the epidural and the gas. Then it will relieve some pain.'. (ID3)

Additional support provided by relatives, the maternity care assistant or manager of the supported accommodation during labour and childbirth was appreciated by some women:

'I couldn't have anything to eat and I was sweating profusely, my lips were completely sweating and I was hot ... [the houseparent] actually got a face cloth and she dipped it, she just cooled down my face'. (ID1)

'I had my midwife... [and then] they brought in, she's like a carer [maternity care assistant], she sits with you, I don't know if everyone gets that but she sits with you through the pregnancy and tries to keep you calm, I had her, she was lovely'. (V5)

A minority of women described their early postnatal experience in a positive way. Both registered and student midwives were portrayed as being very helpful in the provision of information and assisting in the practical skills of parenting.

'Postnatal was brilliant now, it was really, really nice'. (V12)

'Well they [midwives] were very, very good. They were very good with helping me with the baby. Yeah they told me everything I needed to know, they helped me bath her, everything'. (P4)

'There was a student nurse there who was very keen and very kind of like enthusiastic, she was very nice'. (H1)

'They [midwives] did a great job, I mean it now'. (H7)

However, the experiences were not always so positive. Some of the women's negativity emanated from a perceived lack of assistance and support. Midwives and doctors were depicted as unhelpful and un-accommodating to them and their disability needs.

'We [woman and baby] went back to the ward and it kind of went downhill from there'. (P10)

'I am pretty sure about the way that it was managed [postnatal ward in maternity unit] and it was military style'. (H3)

'I can't hear the crying [of baby] myself ... I was very angry over the fact that they [midwives] wouldn't call me and I had to constantly keep being awake, waking up myself to check in case the baby might be crying but you couldn't have a decent sleep, you couldn't rest because you couldn't depend on them, nobody was coming, nobody was checking'. (H10)

Women relayed how difficult it was to get assistance and support with their own self care and parenting skills.

'I had to get my mother to ask somebody to give me a wash, like even a bed bath, just even to clean the blood off me'. (P8)

'She [midwife] told me that there was absolutely no way that the nurses could find additional assistance for me, that they didn't do that sort of thing'. (P3)

'I told the nurse I wanted her to teach me [parenting skills] and the nurse said okay, they showed me how to bath the baby but they didn't teach me anything about bottles or hygiene or sterilisation or anything like that, my mother basically came and showed me how to do that'. (H10)

'Well ... the social worker showed me how to change the baby and then how to wind him and that'. (ID1)

'It's all very visual in hospitals, they hand you information on what exercises to do and they're all pictures...so I wouldn't say I did any of the postnatal exercises because I couldn't see them'. (V9)

One woman with a vision impairment recalled how she sourced information on parenting skills from books. She considered the lack of assistance and support in the postnatal ward as the norm for every woman accessing health services during early motherhood.

'I certainly got no help, I have no family so ... it was myself and my husband and I suppose everything I learned I read in books and stuff, even to bath him and how to change him ... I suppose in some ways I was treated no different than any other patient in the maternity, I was certainly given no extra help'. (V6)

While the women were recuperating in the postnatal period many of their partners would visit regularly to support and assist with parenting. This was welcomed by the women but often the midwives then assumed that the new parents did not require any assistance or support.

'The nurses were going around showing the others [women in the postnatal ward] how to bath their babies but because he [husband's name] was there with me pretty much all the time, it was more 'Ah well she's all right, she's looked after. She doesn't need us. We don't have to worry about her. We'll throw an eye over to her now and again. That's all we have to do.'. (P2)

Women did find the physical skills of parenting very challenging. Midwives tried to accommodate the women's desire to be independent and to address their individual needs, with some success:

'She [midwives] was putting the bath down on a low table ...and she was explaining to me what to do, to support the child's head like and when I was leaving him down to put my spine, to relax and to get enough grip to hold him'. (P12)

'I struggle...the nurses showed me how to bath him [baby] the first time, which was only once...she was showing me how to do it and telling me how to do it and how to dry him and everything like that. And then towards the end when I was leaving, there was one more class but I had decided I could do it'. (ID1)

'A [maternity care assistant] she was lovely, so nice, she showed me what to do, she came into me every morning to make sure I was okay'. (V14)

4.5.2. Assistance and support with baby-feeding

In relation to breastfeeding, difficulty developed when women with a vision impairment were asked to complete a feeding record sheet that they were unable to see. For others, being instructed to observe for the visual signs that the baby was positioned correctly on the breast, labelling the bottles used for storing their milk and locating the correct breastmilk in the communal fridge was impossible.

'I was told there was a technique [for breastfeeding], that you wait till the baby has got a big wide open mouth and then you shove him onto your nipple, I couldn't see whether his mouth was open and I couldn't see where my nipple was'. (V8)

'The whole equipment, the pumps and all the breast feeding with expressing and labels and bottles and fridges, it was all up to me to do it, there was no assistance given, no guidance given'. (V6)

'I found all the freezing of the milk difficult and the labelling and all of that I used to get annoyed and then when I'd have to go to the fridge to get milk out I'd have to go through everybody else's milk to get the right one'. (V6)

For one woman with an intellectual disability, breastfeeding was discouraged. The woman perceived this measure as a mechanism to prevent her becoming attached to her baby before going into foster care.

'They [midwives] didn't want me to get too attached...when they found out I was pregnant, I didn't feel that I was ready and of course then all this fostering came up and then they just gave me a bottle'. (ID1)

Practical assistance with breastfeeding was not always forthcoming and some midwives were described as unsupportive. Trying to communicate and breastfeed simultaneously was difficult for women with a hearing impairment.

'I had to ring the bell every time I wanted to latch [baby to the breast], there was a horrible, horrible older nurse there and I remember her grabbing me, it was like an invasion the way she caught me, it was horrible, just she was obnoxious'. (V10)

'I had to learn how to breastfeed and they [midwives] were asking me all these questions about breastfeeding and... I wasn't able to write down notes back and forth ... I wasn't relaxed because I was trying to communicate with notes, that was very difficult'. (H1)

Some women acknowledged how the midwives did attempt to provide one-to-one care to assist women when breastfeeding but in many cases it was either too little or too late.

'The midwives tried [to assist with breastfeeding] but they were extremely busy, it was just a very, very busy time'... by the time I did get the one-to-one it was almost, it was too late because she [baby] had already latched on wrong'. (V9)

'There's no support, no proper support and I was trying to breast feed and she [baby] kept slipping off and she couldn't latch on, it was quite distressing'. (P18)

For women with a vision impairment who were formula feeding, making bottles was challenging, and their partner was often designated this task. No practical aids were sourced or were available to help measure out the required amount of water and powder when making up formula feeds; one woman used the weight of the bottle as a guide.

'[Husband] would normally do them [bottles], he would make them and he would do them at night or in the morning before he'd go out to work ... and I'd put in the powder and he would put in the water'. (V11)

'Eventually after maybe a week or 2, I started to cop on myself by the weight of the bottle and I used that as my guide like'. (V5)

4.5.3. Assistance and support at home

When preparing for discharge home one woman with a physical disability discussed how a case conference was convened. This was viewed as a positive initiative and resulted in the assignment of a personal assistant, which facilitated her independence.

'There was a big meeting with the public health nurse, the OT [occupational therapist], the social worker, I had an after care worker at the time, doctors they were trying to get what would be best for me ... the OT came in and asked me what I wanted ...there was a list of stuff that I needed to get'. (P12)

However this initiative was not common practice.

'There wasn't any [discharge planning], no one asked me how did I think I was going to cope when I got home being visually impaired. Would I manage to make him [baby] up feeds, little things like even washing or cleaning the umbilical cord, things like that, no... the public nurse, she wasn't even aware I had a visual impairment, the hospital hadn't even informed her'. (V3)

The principal source of support available to women in the early postnatal period was family members or partners. For one woman from the intellectual disability strand, support from her sister was significant in the early motherhood period. While the women were in the maternity unit partners often took time off from work to help with parenting skills, but often this depleted the amount of support available to the woman when discharged home.

'He [husband] took so much time off during my pregnancy for appointments and straight after having the baby that I ended up with no

one at home with me when I came out of hospital. I had to do everything on my own which I don't think it's right'. (V3)

'With breast feeding ... my mum was by far the best help ... I found other people [midwives] almost disempowering, not being supportive, so I was quite disappointed with that'. (V8)

'He [husband] was absolutely invaluable, just even sometimes when I needed help in and out of the shower and in and out of my clothes, I was physically that tired'. (P3)

'In ... the first 3 years certainly if you are visually impaired your partner takes on the role of doing everything with the child'. (V3)

Once discharged from the maternity unit the public health nurses (PHNs) were instrumental in instigating additional support and assistance for a minority of the new mothers. This additional support was in the form of either a home help or a personal assistant (PA). However, the women were critical of how the current role of the personal assistant is one of assisting the mother in her own care and independence but not parenting skills.

'She [PHN] got me home help. It was through her that I got the home help'. (P2)

'I rang the public health nurse, told her I couldn't collect the children from school so child welfare issues arose then I got home help and they collected the children from school and they did a bit of light housework'. (V6)

'They told me no, that the service [of a PA] wasn't for the child'. (V7)

A woman in the physical disability strand employed, at the request of the public health nurse, a child-minder on a live-in basis to assist with the practical aspects of parenting. However, she was concerned about the impact this person may have on the attachment and bonding process between herself and her daughter.

'Having somebody here is wonderful and it's great but she kind of can take over a bit and she's got a great bond with her [baby] and that's terrific and that's good, but... it's very, very difficult watching somebody else do all the bits with your own child, very, very hard. I'm convinced that I haven't bonded with her [baby] the same way'. (P18)

One woman was very complimentary and appreciative of the breastfeeding support received when she was discharged home, a midwife called to see her in her own home and provided support and practical advice.

'The best support I got along breast feeding was when I came home and there was a midwife who came to me for 2 days and she was excellent'. (V9)

Unfortunately not all of the women received this type of support. One woman was quite despondent and pessimistic about the provision of additional assistance and support.

'I've never been offered anything like that [home help or PA] or told anything about that. I don't even know about it really to be honest'. (P4)

'I don't ask for help, you'd want to be fairly disabled in order to get anything in this country'. (V7)

For some women with mental health difficulties there was also a lack of service to meet their needs.

'[Husband's name] was even ringing her [the PHN] up from work, which I didn't know, saying There's something wrong'. And she came around and she said, 'Look there's nothing wrong with you. You're not depressed. You're just tired.'. (M4)

In this particular instance the public health nurse had a lack of knowledge about postnatal depression and said to this woman:

'If I came in now and if you were depressed [baby's name] would be up screaming in his cot neglected because you hadn't picked him up for the last 8 hours and you'd be down here in a state'. (M4)

This women's mental health deteriorated over the following weeks and her access to mental health services was significantly delayed causing severe distress not only to the woman, but to her partner and family.

Not all the women welcomed the additional assistance and support, finding that instead of being helpful, it was disempowering. Women often felt inadequate and unable to care for their baby.

'A letter... from my GP had gone to the health centre, without my consent, saying this person needs extra support and I'm worried about her. I felt totally violated...it was really horrible ... what it was actually telling me was you're not capable of looking after your baby, you're not able to do things'. (V8)

'I was furious about that [extra help provided by home help], really angry about that, it was just it was so upsetting ... I think she [PHN] felt ah, extra help, that will be great, nobody was listening that I was actually doing okay ... of course maybe extra help would be nice but there was a very negative side as well as a bright side and I don't think having a few extra dishes washed and the hoover going around the house was worth the upset, it just made me feel totally inadequate, made me feel like I couldn't look after my baby properly'. (V7)

4.5.4. Specialist support services for women experiencing mental health difficulties

In some parts of the country, there is a specialist service providing support specifically for women with mental health difficulties during pregnancy, childbirth and early motherhood. Women who were fortunate to have this service provided to them found it extremely useful:

'...she [specialist support midwife] will pop up to me as soon as I give birth. She comes round and sees everybody after they give birth, which I think is great'. (M8).

'Then they came up and said we have a bed, we're ready, the surgeon, everybody is in place, we're going to bring you down now and then [my] legs went to jelly and I couldn't move, I said to [name support midwife] 'I don't, I think we'll do it another day or I don't think we'll do this today'. And she said 'That's perfectly normal.' She walked down to theatre [with me]'. (M15)

'[Name support midwife] rang me just to check up on me and she asked me how I was feeling and she said ...if there are any problems to call her'. (M2).

'I think I had a very different experience of pregnancy than most people you know (pause) and [name support midwife] really understood this... any time I needed her, she was there. The morning I was going down for the caesarean, she came into me. She came up after the birth, like you know, and she sat with me and I was breast feeding and she helped me get that going'. (M5).

A few women with mental health difficulties in other parts of the country experienced a lack of understanding from staff in the maternity hospitals.

'They absolutely told me nothing, they gave me no help, no support...I was just another person, and I wasn't even looked at as a person, I was looked at as a hospital bed number ... they treat one person the exact same as the other person'. (M13).

This woman goes on to describe her experiences with members of the health care team.

'One of the nurses came in to me whenever I was crying and turned and walked out and I was sitting at the edge of the bed, like, crying for a couple of hours and the physiotherapist came in to give me all information and I couldn't even speak to her, I didn't know what she was saying and she never even as much as asked me was I all right, not one person asked me was I all right'. (M13)

Another woman's experiences following childbirth were as follows:

'...she sort of came in, she was very cross with me ...very firm, I suppose she, maybe that was just her job, I remember thinking, you know, it just wasn't the right approach for me, you know, because I don't like when anybody raises their voice or gives out, you know, I'd be quite a sensitive person'. (M12)

There was also a mismatch between what this woman needed and what the service thought she needed.

'I was in maybe a couple of days at this stage ...and I just wanted to go and I knew that I would recover better if I was at home... she [midwife] tried to explain to me that ... the reason why I wasn't getting home was because...I was finding it difficult, I was crying a lot and they wanted to make sure that I had the breast feeding...set up properly'. (M12)

Another woman felt that she was stigmatised when they heard she was on antidepressant medication:

'I found I was being watched, do you know what I mean, 'Is she alright with that baby or isn't she.' (M11)

One woman who had mental health problems prior to birth and had been on medication, found the staff in the postnatal ward accommodating, sensitive and responsive to her needs.

'And she took the baby for a few hours to let me have a sleep and that was 'cos I was watching the baby all the time, wouldn't stop 'cos I was afraid of what was going to happen (pause) in case there was anything wrong with her so they were very good'. (M6)

The willingness of the community mental health nurse (CMHN) to ring the maternity unit in the immediate postnatal period was perceived by another woman as helping to maintain her mental health.

'She said 'I [CMHN] will ring the hospital and organise that the baby's taken from you and put in the nursery. You need sleep'. Because a lot of bipolar is linked to your sleep pattern'. (M18)

Some women did not access mental health support services in the immediate phase of their distress because they were struggling to make sense of what was happening to them. As their particular needs were not identified or accommodated, they did not recognise their distress as a mental health difficulty.

'I didn't realise what was wrong with me and when I think of all the times that I cried and I didn't know that there was actually somebody you could chat to, you know what I mean, because I didn't know ... and they're terrible, you're just handed a wee leaflet [on postnatal depression], 'Have a read of that.' What good is that like'? (M11)

'I didn't know what was happening, I didn't know anything, you know, I had no, I didn't think gosh is this postnatal depression. I hadn't even considered because I didn't think I'd ever experience postnatal depression... I kept putting it down to first time mum as well, like maybe I just didn't know'. (M14)

'My postnatal depression affected me in a way that I couldn't bear being in the house on me own and I had to get out of the house as soon as I woke up in the morning because I just was lonely, I was scared, I didn't know what was wrong with me'. (M13)

'I had the baby blues but I didn't realise how bad I was, you know, and the baby was crying and crying and I just couldn't seem to get him settled...'. (M12)

4.5.5. Gaining informed consent

One significant finding to emerge in relation to communication during labour, childbirth and the postnatal period was around the issue of informed consent. Women with a sensory impairment discussed how they often signed forms without knowing what it was they were consenting to. One woman did ask if the consent form(s) were available in alternative formats but they were not, demonstrating a lack of accommodation to those women's needs. Sometimes the woman's partner signed the form; therefore consent was essentially gained by proxy.

'There were [other] forms and things like that; that I just had to sign; nobody really goes through those kind of things with you'. (V8)

'At the time that I signed the form I had no idea what I was signing'. (H9)

'I just signed whatever they [in delivery suite] put in front of me; I didn't know what it meant though... I just signed the page'. (H10)

'I got something to sign that was shaded. I did say I couldn't read it properly but she [midwife] read it for me and I trusted her I guess, there wasn't any jargon ... just consent to information and treatment'. (V2)

'They [PHN and doctors] say injection and I don't know what the injection is for and they just say for sick, so you just go okay, they want to give injection, injection done and just not really knowing. They give you a book but I can't read the book'. (H10)

Some women felt embarrassed or ignored when their partner had to complete the consent form.

'You're a little bit embarrassed ... I wonder do people think I'm illiterate, you feel like standing up and saying 'Excuse me I'm not illiterate, I'm visually impaired.'' (V9)

'I needed to consent for baby to have the BCG [Bacillus Calmette Guerin vaccine], they [PHN] made [husband's name] fill it in the form, they wouldn't let me fill it in ... he did all of that kind of stuff and I wasn't asked'. (V8)

Women with an intellectual disability also discussed how informed consent was not consistently sought. For example, when a public health nurse was performing the Guthrie (Heel Prick) test on her baby, one woman with intellectual disability noted:

'No, (the Public Health Nurse) didn't (tell me). Maybe they forgot to tell me because they are busy anyway you know....I wondered what it was for. (ID2)'

However, in relation to pain management this woman felt she was given an explanation in sufficient depth by the doctor, which enabled her to make a decision and give informed consent.

'I just signed the form, the doctor...told me what could happen to me if I had the needle [epidural]'. (ID2)

Issues around informed consent were not just related to gaining a signature. The women recalled how midwives provided little to no explanation when interventions occurred during the process of labour and childbirth.

'The nurses were lovely, the midwife. But I felt they were doing things [interventions in delivery suite] without my consent. They were going to break the waters, like they didn't tell me ... I was being induced'. (H7)

'I think they [midwives] were lovely, but they didn't really say that much, they didn't really tell you much, they just kind of done their own thing really...they didn't really kind of tell you anything'. (P4)

In contrast, one woman with an intellectual disability described how when her baby was ill while in foster care, her verbal consent for treatment was obtained.

'[Re signing consent for baby's treatment] Well like when he first went up to [name of regional town] they [foster parents] just went to her [foster mother's] doctor, I didn't sign anything at all, I was just asked is that okay and everything like that'. (ID1)

4.6. Person-centred care

A few of the women in the vision impaired and intellectual disability strands provided evidence to suggest that the care provided by health professionals during labour and childbirth was person-centred and accommodating.

'He [obstetrician] just asked me what would I not want to do and I said I wouldn't want caesarean unless really necessary and he said 'That's fair enough.' and that was it'. (V1)

'I got the epidural, I got the needle, and the needle wasn't working the first time and he [anaesthetist] said to me 'Is it working?' He was looking at me ...then he gave me the needle and it worked ... so he was good. I complained about my pain... he was concerned about it. He didn't leave the room till I wasn't in pain anymore. They ... listened ... to me'. (ID2)

Where the health professionals were empathetic and sensitive the women recalled the interaction in a positive light. This positivity was facilitated by health professionals adopting a partnership approach and accommodating to their needs.

'I told her [PHN] that I had [disability] like, she was like 'Oh what can I do for you? How can I make it easy?'. (P10)

'One of the nurses, the midwives... said 'I've heard that the fatigue is the worst.' ... I said 'Yes it is.' and she said 'I'll take him [baby] tonight'. I was just so grateful that somebody understood that I needed to sleep. Half of me felt like kissing the woman, I thought 'You're a saint". (P6)

A number of women reported feeling disempowered, scared and were unable to comprehend why their hearing impairment should impact on the quality of communication and information exchanged between them and the midwives.

'We [woman and partner] didn't know what was going on, it was kind of scary'. (H12)

'It shouldn't matter to them [midwives in delivery suite] if you are deaf or hearing, they should still be prepared to communicate with you and explain what they are doing and what is going on, maybe they don't know how to communicate with deaf people'. (H8)

Often it was the assertiveness of their partner that changed the dynamics in the woman/midwife relationship and the exchange of information that occurred thereafter.

'My husband is very assertive, he is very willing to say 'What is going on? Please repeat.' We hate for people to say 'Oh fine.' and then just to walk off, so we are very assertive in reminding people and insisting that you tell me, talk to me, you have to push yourself, you have to be pushy'. (H8)

A number of the women provided evidence to suggest that the maternity units or health professionals did not recognise or accommodate the uniqueness of the women's needs. For one woman with a vision impairment her sense of disorientation was exacerbated when using the gas and air method of pain management.

'When I took that gas and air thing ... everything is just white and you think am I dying, is this the light I'm supposed to see and you stop... if someone had of said to me you're going to feel a bit woozy ... that would be good'. (V1)

There were a few instances of health professionals' insensitivity and lack of awareness of the need for person-centred care. The breadth of organisation and preplanning needed before attending for postnatal or paediatric appointments, for example, caused huge anxiety and financial loss for one woman attending a paediatric unit, which went unrecognised by her carers.

'We ... might be only home 2 or 3 days from the hospital and she [consultant paediatrician] could ring and say, this could be half 9 in the morning, 'Can you be up here for surgery at 2 o'clock?' [paediatric unit was in a major city and woman was living in a rural area]'. (V14)

'We were heading out the door literally...to stay overnight to have this examination under anaesthetic done first thing the next morning, just as we were getting on the train [paediatric unit rang] we were told that that appointment was to be cancelled.' (V14)

Some maternity units were accommodating and flexible in their policies and procedures when addressing the women's individual needs.

'[Husband's name] had a 24 hour kind of pass, so he was allowed visit at non-visiting times which was great'. (V8)

'I was allowed to change her [baby] on the bed [not usual policy] and I think that might have been due to the fact as well that I had got a disability'. (P9)

But this was not the case in the majority of units. Some units were very inflexible in their policies and procedures.

'I had to kick him [husband] out at 9 o'clock, your man [security guard] is there saying 'Come on, come on, come on, partners out, partners out.'...so I'm panicking going 'How am I going to lift him [baby] out of the cot?' I didn't know how I was going to do it'. (P2)

'[Baby] started spitting mucus stuff and I was afraid I wouldn't be able to see [him] and I asked someone to take the baby for that evening and they didn't want that'. (V3)

Some procedures and policies were inappropriate or insensitive to women with a sensory impairment.

'Every time they were given medication, they [midwives] would continually get me to check the wrist band [baby's identification] with them...I couldn't read their numbers or their codes, I could confirm their name and address but I certainly couldn't confirm their file numbers and things like that'. (V6)

'You have to have a car seat to bring your baby home, why would I buy a car seat, I don't have a car...it just didn't make sense'. (V6)

This woman defied the policies and procedures on occasion:

'I defied the rules and I changed the baby on the bed because I wanted to be able to see the baby to change him'. (V6)

'I discovered a sponge in [shop] that you lay the baby on, I brought it in [to the maternity unit] with me and... they [midwives] didn't like it because health and safety... everything is made an issue of'. (V6)

4.7. Conclusion

This chapter has presented the women's experiences of accommodation during their contact with health services. Their experiences were mixed, with many stories of empathetic and sensitive staff assisting women during pregnancy, childbirth and early motherhood. A number of key issues were highlighted, however, including the need for sensitivity and awareness when giving information to women with a disability. It was noted by many that little reassurance was given by staff unless it was asked for and person-centred care was lacking in many instances. In particular, women with an intellectual disability required far more one-to-one explanation and advice. The importance of sign language interpreters was emphasised and women valued their presence. A clear need for women to have an assessment of mental health needs was identified and in those areas of the country where specialist mental health services are available, they were much appreciated. Lastly, women felt strongly that policies and procedures should be flexible for them, to improve their experiences of care. Despite the identified failings, women stated that they were slow to complain, which means that their voices are not usually heard by the main clinicians working with them.

Chapter 5 Findings from interviews with women

Theme Four: Acceptability and attitudes

5.1. Introduction

This theme of acceptability and attitudes describes the relationship established between the women and the health service providers during pregnancy, childbirth and early motherhood. Key areas identified by the women as important were: interpersonal relationships and interactions with health professionals, attitudes of, and communication with, health professionals, health professionals' knowledge and understanding of disability and impairment, and developing parenting skills.

5.2. Interpersonal relationships and interactions

5.2.1. Introduction

Establishing and building a rapport was considered an important element of the relationship established between the health professionals and the women. The women interviewed identified how being treated in a respectful and dignified manner was critical in their interactions with health professionals and others they met when accessing the health services. The women expressed a desire to be treated as any other person accessing and availing of the services during pregnancy, childbirth and early motherhood. Not being treated any differently to any other women was important and afforded them a sense of normality, which many appreciated because, for once, their disability was not perceived to be their defining trait.

A few women, however, considered the large number of people attending the services and the constraints of limited time as key factors that impacted on their experiences. They described how they felt 'like a number' and not a

person with feelings and emotions when accessing the health services. For some women experiencing mental health difficulties, psychological and emotional support were not always available.

'Just the midwives don't have the time in the postnatal wards I don't think to really talk to people and see how they are getting on. I think they look after the physical side of things and they haven't really got the chance....I don't feel that the staff were given the time'. (M16)

'...one night I was really distressed and I remember holding the buzzer and they were getting quite cross with me...'Pull yourself together, this is ridiculous, like we can't sit and feed your baby all night, you have to do it.''. (M14)

'I understand when it comes to hospitals, I understand that people can be busy, but it only takes 2 seconds to say 'Are you okay? Can I do anything for you?' You know what I mean like. They don't do that anymore, you're just get in and get out and away you go'. (M13)

5.2.2. Interpersonal relationships and interactions with midwives

During the individual interviews the women did not differentiate between nurse and midwife, frequently referring to the midwife as nurse. The majority of women interviewed were very complimentary of the care they received and the interactions that occurred with midwives. In particular, when asked to describe their relationship during labour and childbirth, the women did so in a very positive way, using terms to describe midwives such as '*really, really good*' (P2), '*very helpful*'. (P7), '*fantastic*' (P9), '*wonderful*' (P3), '*lovely*' (M11), '*very, very compassionate and comforting*' (H3). Other descriptions included:

'The 2 midwives [in delivery suite] they were students and again they were lovely, lovely girls, they were really nice, things were okay there [in delivery suite]'. (P5)

'In the delivery room, brilliant midwives ...absolutely brilliant and very, very, very clued in, they were really good and gave a lot of confidence and that was great'. (V8)

'I got on great with them [midwives]. They were all nice to me'. (ID2)

'The nurses [in the maternity unit] were fine, they really were'. (ID1)

'They [midwives] were just brilliant. They made the effort to make sure that I knew they were going to speak to me or the nurses made an effort of touching my arm or bending down and talking to me'. (H5)

This positivity may, in part, be due to the continuity of carer policy implemented in the majority of delivery units. In other areas of the maternity hospitals, comments were less complimentary. A small number of the women were upset by their encounters with the midwives.

'As soon as I went down to the ward [postnatal ward] the attitude was so different'. (V8)

'Unfortunately one or 2 of the ward sisters were very, very difficult'. (P3)

'You feel belittled by them [midwives]'. (H4)

'I'm his [baby's] mother and I should have been listened to ... and sometimes I think if I was a hearing person and my husband was a hearing person I think I would have been respected more'. (H7)

The majority of women with a sensory impairment described how interactions with midwives in the postnatal area were impeded by a lack of awareness and sensitivity around their impairment:

'I felt that they [midwives] didn't care about my communication needs because I was deaf...it was a problem to them...I wasn't able to... communicate ... and the nurse was ignoring me and not bothering'. (H9)

'There was no words coming out of her [midwife in postnatal ward], just a smile...it's like she couldn't communicate with me ...I think it was because she probably never dealt with a deaf person before'. (H14)

'No one told me where the nursery was. I couldn't read the signs on the doors. I asked the nurse ... she was so ignorant... I was stupid, can I not see the door? Despite [vision impairment] being on my file'. (V3)

'You don't ask them [midwives] questions because they're too important for that, they're too busy, don't be asking stupid questions, go in, do as your told and get out, that's the impression you get'. (H4)

Ineffective communication also impacted on the establishment of trust between the health professionals and some of the women. This caused 2 women to question whether or not they were receiving the correct medication.

'They [midwives] were giving me tablets left, right and centre and they kept telling me that they were blood pressure tablets and I don't know what they were because every day they were different tablets...at one stage I pretended to put them in my mouth and I kept one and I asked my partner what is written on that and he says 'Nothing, just a little orange tablet'. (V5)

'They wanted to give me some tablets [for blood pressure] and I didn't take them because I didn't know what they were and I wasn't able to communicate with them'. (H12)

5.2.3. Interpersonal relationships and interactions with public health nurses

Interacting with the public health nurse was also described very positively by the majority of women, using terms such as *'really, really nice'* (H7), *'very friendly'* (H4), and *'brilliant, absolutely brilliant'* (V6).

'The public health nurses were fantastic. For the first 3 weeks, I got maybe 2 visits a week from her, so that was fantastic'. (P3)

'She came out [to supported accommodation] and checked on the baby'. (ID 2)

'She was excellent and I felt that she was definitely very aware of my history and quite careful'. (M15 (3rd interview))

When asked what made the interaction with the public health nurse so positive the women described the public health nurse as *'just nice'* (M7) and *'not intrusive'* (M18).

'She really assured you of what was going on and what was going to happen and she said 'Shortly you'll be spoon feeding him.' and advised what you could give him. I found her very helpful...she was like a mother, she was like talking to me, this could be my daughter, this is what she could be going through'. (H13)

'She asked me just about how I was getting on really and did I have any problems and questions ... she just went through things ... giving me a few tips and that around parenting and putting my name down for a parenting course'. (P4)

'She just weighed him [baby], she talked about his milk and if he was feeding and everything like that'. (ID1)

'I felt it was easy to talk to her... she knew about my history so she made it her business to call with me every couple of weeks to make sure that I was okay'. (M12)

Some of the public health nurses (PHNs) were described as sensitive to the woman's individual needs and flexible in their implementation of policies or procedures governing the provision of care.

'They were looking at me all the time when explaining things and said 'do you understand?'. (H13)

'She said 'I'll give you my number but don't give it to anyone else.' and I'd text her if I had any problems'. (V14)

'There's never an issue about them [PHNs] calling to the house'. (V6)

'She [PHN] asked me what were my needs and she rang the HSE to try and ensure that the PA [personal assistant] service which I have was extended. I absolutely couldn't fault her'. (V9)

However, not all of the women had such a positive experience, or a good relationship, with the public health nurse. A sizeable minority described the public health nurse as uninterested, inconsiderate and inflexible.

'They [PHNs] treat you as if you can't be like decent, proper parents because you're deaf and that you're not able, it's quite offensive. So I wasn't keen to get back in touch with the public health nurse'. (H1)

'She [PHN] is quite good but ... she kind of gives you a blank reaction, so you don't know whether you are doing something wrong or ... right. I'm kind of watching what I'm saying and ... walking on egg shells'. (P7)

'She [PHN] had very little interest in being here [woman's home] so she never came very often'. (V10)

'She [PHN] was very pass-remarkable. Saying things like 'Bathing your baby is a way of bonding with your baby.' and I said 'Yeah but I can't

bath him. I just can't.' and she says 'Oh well if you don't bath your baby then you don't bond with them.' That really upset me...'. (P2)

'She [PHN] was very impatient ... I tried to ask her questions... I said 'Stop for a minute I want to talk about this.' but no she wanted to go through, 'How do you feel?' la, la, la next, next, next, tick the box. (H8)

'She [PHN] was an absolute, she didn't give one hoot, she was dreadful, she couldn't have been any worse. I mean I just can't describe how bad she was'. (M1)

'She [PHN] ...spent a good hour the first day ...asking was I referring myself to the mental health services again and what was I going to do about this ... a doctor, and what was I going to do about the other, so I felt that I was ear marked for, special attention is not, extra scrutiny is probably more accurate'. (M15 (2nd interview))

'She [PHN] was terrible, she kept saying about, she knew I was on ...tablets and 'You'll be grand. You'll get over it.' [postnatal depression] you know, 'You'll get over it.' like and I was, like, 'What?'" (M11)

Others recounted how the public health nurse focused mainly on the woman's disability and on whether or not the baby would inherit the same condition.

The information provided by the public health nurse was often described as unhelpful and inappropriate.

'The public health nurse ...wanted to know was the baby deaf or hearing, she was kind of very preoccupied with this, she really annoyed me ... I said 'It doesn't matter if the child is deaf or hearing. It's my baby, deaf is grand, same as me, I don't mind.', ...and she just kept on going on about this hearing test ...problematizing it the whole time, making it into this big issue when it wasn't one for me'. (H1)

'At the time I was expressing [breast milk] because my nipples were very, very sore... and the public health nurse said 'The reason why it's sore is because you've got red hair.' and that wasn't particularly helpful. She would interfere ... she was taking the baby out of my hands and shoving him on... it was actually only my mum that just sat down with me and said 'I know it's hard, just try it again.'... that was all that was needed. To my mum I wasn't a blind person, I was her daughter who was struggling feeding and she had gone through it all and she had experienced it being painful'. (V7)

For women with a hearing impairment the interaction with the public health nurse and exchange of information was enhanced when a sign language interpreter was employed.

'[Husband's name] went to DeafHear... so they organised the interpreter and the public health nurse came and the interpreter and she did the baby weight and the heel prick test and everything and thank goodness that the interpreter was able to come because that was very important'. (H12)

5.2.4. Interpersonal relationships and interactions with doctors

Similarly, there were some assenting narratives describing women's experiences of interacting with GPs, and obstetricians in the maternity units.

'A real gentleman [obstetrician], he does as much as he needs to do, he kind of takes his lead from you'. (V9)

'She's [obstetrician] a lady, a lovely, lovely woman'. (V10)

'The obstetrician, he was very nice, what he was saying was excellent, he was a very kind person and I trusted him, really, I trusted him a 100%, which was a great feeling'. (P6)

However, others were less positive. One woman with a hearing impairment recalled how the doctor, in the maternity unit was unwilling to engage with her and her partner when they asked about their son's condition. This resulted in them feeling uninformed.

'I had a doctor [in maternity unit] who was dismissive and rude. Nobody would give us any information, leaflets, nothing. The doctor... didn't want to speak to us... he was too nervous...I'd say ...'What's going on?' ...and he would say 'He'll [baby] be fine. He'll be home in a day or 2.' and then he'd walk off. There were hearing parents on the other side of the ward and he made the effort to speak to them'. (H7)

The women interviewed described encountering significant challenges in terms of different accents, formation and pronunciation of words when communicating with health professionals who were non-Irish nationals.

'Quite often they'd be non-Irish medical staff and it's just very difficult to lip read people with strong accents or unfamiliar looking kind of faces, lip reading is very, very difficult, very arduous in the first place, so it makes it that much harder'. (H1)

'A lot of the time you were dealing with foreign speaking doctors so it was quite difficult to understand a lot of them. Even if they were explaining it you wouldn't have a clue what they were saying'. (V14)

One woman recalled how the GP questioned her inability to hear the spoken word, which was very upsetting and distressing for her.

'He [GP] questioned my hearing. He said 'You can hear me now. Why can't you hear the phone?' It's very inappropriate like, I'm sick of explaining ... that I'm partially deaf but I can hear with a hearing aid but I can't hear the phone and I have problems when talking to more than one person... I was really annoyed...I'm not going back to him'. (H7)

The 6 week postnatal examination was described as fragmented, rushed and hurried. For one woman, not meeting with the person who was present at the birth of her baby was a source of great stress and anxiety.

'I had the 6 week check up and it was very much inconveniencing them [doctors]...It was very rushed, very hurried. I was asking questions, it was difficult because I was seeing the person who hadn't actually delivered the baby, it was a bit fragmented'. (P11)

When ineffective communication methods were employed the majority of women with a disability felt disempowered. Some felt embarrassed about being unable to communicate effectively. Disempowerment was intensified when health professionals adopted an authoritarian approach, resulting in the women relinquishing their sense of control and expectations.

'I had been arguing with them [doctors in maternity unit] for so long, I just thought you know, do it your own way [mode of delivery], once you don't damage the child'. (P7)

'It was quite upsetting because I couldn't really communicate very well with him [doctor in maternity unit] and I was sort of embarrassed ... I was very impacted, I felt like they saw me as someone who is very stupid, I'm a confident woman generally but ... my confidence was totally diminished ... I felt humiliated'. (H11)

5.2.5. Interpersonal relationships and interactions with other health professionals

Discussions around the interpersonal relationships and interactions with other health professionals, including an anaesthetist, paediatric nurses, a paediatrician and social workers, generated mixed responses. Some were positive:

'The anaesthetist was so sweet ... I said 'I've an awful fear of going through labour again.' and he said 'Well you're not going to be afraid this time. It's going to be so controlled and managed.''. (M2)

'In the [name of paediatric hospital] the nurses really tried, they were very helpful, we had an interpreter, they tried to make sure I had the information, they took time to write things down... they gave me a lot of support'. (H1)

'The paediatrician was lovely. Very warm, very caring, he introduced himself, he congratulated me and then he done all his checks and he was explaining as he went through it'. (V12).

'The nurse actually that gives the vaccinations [practice nurse], she's very good and really nice. Never in a hurry. She takes the time to explain the vaccinations and the side effects... she's very good'. (V7)

Women who were fortunate to attend the specialist mental health service within the maternity service did not feel the isolation that other women encountered.

'And I just feel like I have a backbone there backing me up and I know if I'm ever really, really bad I can always have someone to turn to, which is the most important thing. And she [specialist midwife] just has a lovely homely, warm feeling to her ...when I first met her she said 'You're grand. You're managing fine.'... I know she'll be up at my bedside as soon as I give birth ... she's there now if I need her'. (M8)

'[Name support midwife] did come in before I left, and she went through postnatal depression and gave me leaflets and the signs to look out for and to contact her if I had any problems or anxieties or anything. I was very lucky. The service I got was fantastic'. (M5)

'They [midwives] make you take a survey [EPDS]... before you're discharged, on how you're feeling in the last few days... they seem to be very aware in there [maternity hospital] and on that leaflet as well there's like postnatal depression as well'. (M9)

Women who attended a specialist service for women with postnatal problems, situated within the mental health services, also spoke very positively about the support.

'I started coming here... in December maybe, and yeah I found it a help, I think just being able to talk to somebody and somebody understands how you feel like, you know, it really helps'. (M12)

One woman who was attending a generic mental health service spoke of feeling very supported both emotionally and practically.

'The people in the psychiatric services were great... I can't go to the day centre anymore, I can't bring the babies with me. So they come and see me... maybe once a week and they might stay for an hour and if somebody needs a bottle they will pop the bottle in or they might say to me 'Do you want to go and have a shower?', and I'd go and have a shower while they keep an eye. Or they'd make me my lunch'. (M16)

Some women were quite negative when commenting on the interactions with other health professionals they met in the publicly-funded health services, including paediatricians and social workers:

'There was one doctor, a paediatric doctor and I found him very hateful ... he wanted to examine her [baby] and he just pulled down the blankets and just ripped open her clothes ... and then he started to feel his way around the arm and she was screaming. Then he was looking down at the bed but he was talking to the 2 of us ... and the glasses pulled down, he said 'Are you people with medical background?' I said 'No we're just her parents.' ... so, obnoxious basically'. (H4)

'The social workers walk all over me, every time they talk to me they say the same thing... I made the one mistake, I left [baby] on a couch but I wasn't far away but I've learned from that day onwards never to say anything to them because it goes back to [multidisciplinary case conferences]. Even if I told her something... personal... in confidence, she will go back and say it to them I don't trust them anymore'. (ID1)

'He [social worker] makes me feel very eh ... eh ... down. He goes on all the time getting at me you know instead of kind of helping me and saying to me 'Well you are doing a good job now with the baby.' ... I felt worthless and ... he made me feel like I couldn't mind the child ... He made me feel I wasn't a good mother'. (ID2)

'... they [practitioners in the mental health services] ... just throw medication at you and 'Take that and you'll be fine.'. (M7)

The women recounted how, although different methods of communication were employed, communicating with health professionals was still extremely difficult and challenging, using words such as *'really awkward'* (H10), and *'very poor'* (V5), . Many women felt as if the health professionals were not listening to them.

'In the hospital I wasn't believed, I wasn't listened to'. (P8)

'Going through the actual birth it was just a lot of commotion and fussing and totally just confusing. I'd no idea, I never heard anything at all, nobody said anything ... I didn't know what was going on'. (H10)

Spoken and written words were the primary methods of communication between health professionals and women with a hearing impairment. However, these were not always the most appropriate or effective methods, nor were they acceptable to the women.

'We did everything through written, writing to each other, the GP didn't provide an interpreter and I had to keep on stopping him to say 'Sorry what does this mean? What does that word mean? What does this mean?', trying to translate all the time'. (H11)

'I can read, but very slowly, what would take you maybe a minute to read it might take me 10 minutes, because I read it word, letter for letter practically. I scan along the lines'. (V1)

'For deaf people, their first language is sign language and their second language is English ... I decided not to ask the questions that I had playing on my mind because I ...didn't want to write them down and make a fool of myself by using the wrong English grammar'. (H11)

Other non-verbal communication techniques were used by both health professionals and the women as an alternative means of communication.

'I'd press the button to call the nurse and I would just kind of point and pull a face... gesturing and facial expressions'. (H12)

'Just little hand gestures'. (V14)

Some health professionals were apparently quite insensitive to the woman's individual needs; they looked away or walked away while still talking to the woman, rendering the interaction ineffective and unacceptable.

'He [consultant obstetrician] mumbled ... he was going up the corridor ... I said 'I'm very sorry doctor' I said 'but I am partially deaf and you are mumbling under your breath to me constantly and I just don't know what you've said.''. (H4)

'I was trying to catch what the nurses was saying. I wanted to talk more but they were gone, they would walk off, walk away'. (H8)

'When the paediatrician came in after I'd had [baby's name] and ... he walked to the window ... and looked out of the window and spoke to me with his back to me ... I couldn't believe he could do that to someone'. (H5)

The women recalled how generally the health professionals displayed a lack of awareness of the communication difficulties women with a sensory impairment may experience.

'They [midwives and doctors] ... were just saying 'Here this is not going to work.' and just ignoring the communication all together, and just hands on and doing [the antenatal assessment]'. (H9)

5.2.6. Health professionals' empathy and sympathy

Empathy and sensitivity were described by the women as central elements of any interpersonal relationship, informing attitudes of and interactions with the health professionals during pregnancy, childbirth and early motherhood. These elements were not, however, always apparent within the relationship.

'The midwife... would always say 'Can you hear that? Can you hear that?' and I didn't like her saying that... she knew I was deaf. (H11)

'They were asking somebody that was blind could I see colours'. (V5)

'I was so worried the entire time I was there because I have a relapsing form of [MS] and I knew that if things went too hard I could end up back in bed for months. I explained all this time and time again to the doctors and they were just ...there was no recognition of the disability'. (P3)

'One midwife was extremely abrupt... she said 'These people [maternity care assistants] are very busy. You have to get up and get your own bottles.' and blah, blah, blah and she was really rude'. (V9)

In 2 instances, women who were partially sighted were upset at what they perceived as an over-emphasis on their disability:

'I did have one doctor one time escort me to the door and I got really upset over that and I said it to the sister [unit manager in maternity unit] I didn't like what he did, I'm not blind, I don't need to be escorted'. (V6)

'They're [midwives and doctors] inclined to catch me by the arm or try to, you know put my hand on something... they have no concept that I can see, and that makes me feel uncomfortable because I'm not blind and I don't need that sort of assistance'. (V9)

But there was some consensus that some health professionals did display empathy, sensitivity and an awareness of the specific communication requirements of women with a hearing impairment.

'He [doctor] went out of his way...very helpful and very nice'. (H4)

'He [doctor] was a very nice man, he wouldn't rush you, he would take his time...he was calm and would explain any of the treatments.' (H8)

'She's a good GP, she'll sit there and she'll explain everything to me face-to-face, I'm very comfortable with her, very happy with her, I find her very good'. (H13)

5.3. Health professionals' attitudes

5.3.1. Health professionals' attitudes to pregnancy and disability

Becoming a mother was a desire for many women. This was apparent by the fact that the majority of couples planned to become parents. However, some

health professionals appeared to be more intent on dissuading the woman with a disability and her partner to forgo parenting.

'He [neurologist] didn't really encourage me to have children'. (P11)

'The neurologist seemed to think that I was extremely foolish and that it [MS] would get worse. It always seemed to me that he assumed that I wasn't having children'. (P6)

'It wasn't until I met my obstetrician that it was kind of like 'What have you done?' ...the minute I walked in it was like 'How long have you this [disability]?' and it was just, like, 'Oh God'. It was like this man did not understand why I was pregnant ...I was kind of like taken back and I was kind of going 'Oh no what have I done? Am I going to die?'. (P1)

One woman with a mental health difficulty, who took part in the pilot survey, and who was accessing mainstream mental health services, reported that she left the services once she became pregnant because of the negative attitude she experienced from the psychiatrist when she revealed her pregnancy.

'My psychiatrist said not to get pregnant and to come down off my medication first anyway. .. I got pregnant. I said it to my psychiatrist and he said 'Was there a breakdown in the English language?' I found that a little bit offensive. The way he put it, 'Was there a breakdown in the English language?'... we decided to take control of our life and to try and have [baby's name] and so that was the end of my relationship with my psychiatrist. Basically he said 'You don't need me anymore then.'. (MPilot)

Not all women experienced such negativity; some health professionals did support the woman's/couple's decision to become a parent/parents.

'He [GP] was great and he was saying, 'I don't think you will have any troubles.'. (P1)

'It was mostly midwives that I was dealing with, fantastic, very supportive'. (V13)

'The prosthetic doctor that deals with me ... when I rang about a problem with the leg and told her I was pregnant she had said 'Well, just like mind yourself, if you need to come in...' because your body does go through a lot of changes when you are pregnant'. (P9)

'One [neurologist] said 'Get on with your life. Don't wait around, for the next big relapse, just get on with your life.' (P10)

'They [neurology team] were thrilled I was pregnant. He [neurologist] does say to people 'Go ahead and get pregnant. It's not going to make your [disability] worse.' (P17)

A significant number of women reported encountering inappropriate attitudes and behaviours, which were both subtle and obvious in nature. Negative and prejudicial attitudes featured prominently and consequently the women felt disrespected.

'It's just subtle attitudes from people like you hear people saying This pregnant woman with a guide dog', there's almost kind of horror and it kind of makes you feel kind of grotesque'. (V8)

'I was saying to him [doctor in maternity unit] ... 'Can you explain that to me please?' ... [his reply] 'I'll discuss it with you in a minute.' was ... kind of very sharp, kind of 'No I'm doing something.' and I'm worrying if there is something seriously wrong [with baby]'. (P7)

Health professionals were often described as *'patronising'* (H7), *'paternalistic'* (H12), *'not friendly'* (V14), and *'arrogant'* (PD7), which made their experiences *'harder and stressful'* (H7).

'... the old, very old school, you know 'I'm going to do it my way, this is the way you do it, you do it my way.' ...kind of, they'd ask 'How are you going to manage this baby?' and did you have help and stuff. I wanted to go home as early as I could'. (V8)

'They were complimenting me and saying how marvellous I was and quite patronising, you know how brilliant I was because I was blind and I was doing all this and of course I was lapping it up and in the back of my mind I was like 'eejits!'. (V5)

'I just felt that I was bossed around by certain people [health professionals in psychiatric unit]'. (ID2)

'I felt normal when I had the baby, I felt just like one of the masses of other women who have babies and then I immediately felt like a problem with her [PHN]'. (P6)

'She [PHN]... said 'Oh you're deaf.' and I said 'Yes I'm deaf'...it was just her facial expression she was very... kind of patronising and she

said 'How will you hear the baby?' ...it was like she really perceived me as having a deficit...I didn't like her attitude, I really didn't like it'. (H11)

Women described how they encountered insensitive and derogatory comments from health professionals. Sympathy and pity were common emotions exhibited at each juncture during pregnancy, childbirth and early motherhood. Such comments and behaviours impacted on the women's self-confidence, self-esteem and self-efficacy, causing them to doubt their own ability to be good parents. Many women recalled how health professionals lacked disability awareness.

'There was a lack of wanting to understand the disability'. (V3)

'I thought they could have explained more but I think that was down to ignorance, being honest, ignorance of being blind and what that meant'. (V5)

'I think they [midwives] were thinking 'Poor girl, she's going to end up in a wheelchair.'. (P6)

'Basically [the obstetrician] said to us 'I help loads of disabled women to get pregnant but they've all had accidents which made them disabled. None of them had genetic impairments.', so basically he was saying that if there was any risk, he couldn't guarantee that we wouldn't have a disabled child, he didn't want to know'. (P5)

'One midwife... I think she thought that I was just a bit of an idiot. I couldn't understand her lip reading, she was getting impatient with me ... she kept sighing and tutting, my self-esteem and my confidence just hit the ground... I felt like I wanted to cry, I kept having to control and stop myself from tearing up and crying'. (H11)

One woman felt she was labelled:

'There's an element of misunderstanding, I think they could have perceived me as being very demanding, just labelled as demanding'. (H3)

Frequently the woman's individuality was not recognised and often they were referred to in the third person; this was exemplified by health professionals having a tendency to communicate with the woman's partner or relative, who accompanied them to the maternity unit, rather than with the woman.

'Some members of the staff wouldn't talk to me because I'm deaf and they would talk to another nurse and I'd be sitting there going 'Look, I'm here you know.', feeling frustrated'. (H8)

'I would go [to maternity unit] with my mam; I always had somebody with me. They [midwives] kind of talked to my mam, 'Is she, has she?' sure my mam wasn't pregnant, how did she know, she wasn't feeling the signs'. (V5)

'All they [midwives and doctors] were concerned about was that I was pregnant and I was having a baby, they weren't interested in how difficult it was for me to get to appointments, how difficult it was for me ... what I would perceive to be major difficulties'. (V3)

'They [midwives and doctors] talked over me an awful lot of the time... no matter how many times you said 'Hello I'm here, yeah I'm in the room.' It was still kind of 'Very well, this has to be done with her and that has to be done with her.'. (P7)

The women considered these actions as rude and they felt ignored. In one case the woman's companion encouraged the midwives to redress their actions.

'My mam is like 'Well, do you want to talk to her yourself?'. (V5)

5.3.2. Health professionals' attitudes to screening for inherited disorders/disability

The women interviewed reported how health professionals' attitudes and perceptions framed the relationship established with them. Often their view of the woman's disability and its affect on her baby appeared to take precedence over caring for her.

'After the child was born, just a new baby, the first thing they start talking about was the hearing tests'. (H1)

'He [paediatrician] just wanted to find out about the sight loss...he just wanted to find out if it's genetic, how would the child be affected by it ... and I said 'I know she would be a carrier but she wouldn't have it'. I found it strange that they were...so worried and so concerned'. (V1)

'He [paediatrician] just walks in the room and he didn't introduce himself or anything and he just looked down on his form and he said ... 'Your deafness, your deafness how was it caused?' I just stared at him because I wasn't registering what he was saying ... I sort of managed to pull myself together and say 'Eh, nerve damage.' ... at no stage did he say who he was. He just walked in the room and that was the first thing he said to me'. (H5)

'I remember, when the child did have a hearing test the attitude of the professional staff was 'Oh, that's great, the child is hearing, thank God, thank God, thank God, your child isn't deaf'. And I was like, 'Excuse me, I'm deaf. Have you noticed?'" (H1)

Some women did enquire about the possibility of their baby inheriting the disability or impairment.

'I asked the question 'Could my child ... inherit the disability?' and they didn't seem too interested. The paediatrician didn't seem to even know or understand the disability'. (V3)

'I just wanted to know was there a test [impairment heredity], was there anything, what were the chances and he [GP] said 'I'll look into that, I'll ask one of my colleagues.' The next time I asked again he hadn't done it and the next time I asked he kind of just dismissed it'. (V10)

For some of the women, screening was often offered or suggested in the early postnatal period.

'They [paediatrician] kept emphasising that I needed to check to make sure his [baby's] hearing was fine and then they made appointments for him to check his hearing. If you think about it, 90% of deaf children are born to hearing parents. And I just feel it all comes back to my hearing, not the fact I'm a new mother, just about me and my hearing problem. I was a bit down about that'. (H7)

'They [midwives and paediatrician] asked me about the hearing test but I refused. I think ... whether the baby is deaf or hearing just leave it in its natural state and not be interfering in that way'. (H11)

'I have no problem in erring on the side of caution, I've no problem bringing my children back for appointments when they need them but don't these people [paediatricians] get that you're either born with it [eye condition] or you're not'. (V9)

In one case when prenatal screening was offered it generated a great deal of stress and tremendous upset for the woman and her partner.

'Practically all of them [doctors and midwives] asked me ... about the condition. Then it was like 'Well the child, will that have the same sight?' and we said it's a 50/50 chance and one person asked me would I consider pre-implantation screening. Pre-implantation screening, warning bells going off in my head, is that legal? I got really, really upset and really insulted by that, it suggests that being blind is something so horrific and so horrible that you'd be willing to abort a child It felt really, really upsetting. It's abnormal in my family to be able to see'. (V8)

One woman actually perceived that the health professionals held her responsible for passing on the disability to her baby.

'The attitudes [of paediatricians, GP and PHN] was just appalling I felt like they were blaming me, I felt like it was really all my fault, hearing or not, this is the question, hearing or not and this is what everyone wanted to know and then you have to keep having all these hearing tests, every 6 months...and I didn't want to do that, I don't want to put my child through it'. (H1)

5.3.3. Health professionals' attitudes to parenting and disability

Even before birth, at the moment of pregnancy diagnosis, a few women's ability to parent was tacitly questioned:

'The first question he [GP] asked me was did I want to keep it [baby]...It was that I was in a wheelchair and I hadn't a partner. (P12)

A number of women recalled sensing that health professionals had little faith in their ability to carry out the physical skills of parenting and had a tendency to be judgemental about their ability to parent.

'A lot of questions on 'How are you going to manage?' and 'How are you going to look after this baby and are you going to be able to do things?' ... they [midwives] wanted [husband's name] to bath the baby, not me and I actually really didn't like that because I'm confident at bathing a baby ...I love it, whereas [husband's name] wouldn't be confident'. (V8)

'If you're diabetic or even a bad leg you can be a parent, you know what I mean, so why is it that if you're depressed, why can you not be a parent? ... you're on tablets, you're trying to deal with it and you don't need people judging you, as if you're going to throw your wee one out the window or something'. (M11)

'The nurses were going around to all the other mothers in the ward [in maternity unit] and saying 'How is she going to cope with the baby?' Then other mothers would say 'They shouldn't be having babies.'. (H7)

Consequently some women felt their parenting role and skills were constantly under surveillance. They felt health professionals were continually watching, observing and judging them on their ability to parent.

'The first time I did it [changed the baby's nappy] I was an absolute basket case, there was [husband's name], myself, there was the physiotherapist, there was another 2 physiotherapists observing and the ward sister and here was I expected to change a child's nappy with 10 pairs of eyes on me, being judged like, it was just, it was ...absolutely horrible'. (P18)

'They [midwives] were watching to see could I cope [with baby]'. (P12)

'I always felt like there was somebody watching me ... somebody kind of hovering over me, which was a very uneasy feeling, I was kind of like I can't wait to get home because you know then I can be on my own, kind of thing'. (P7)

'I felt that they [midwives] judged me all the time'. (H7)

'[The] paediatrician ... was great but she was watching me, she asked me to put the baby's clothes back on and I felt like I was being observed'. (V8)

'There was occasions where it was kind of said 'Look we need to sort the situation out because it could become a child protection issue.' and they [PHNs] were saying this to me when I was pregnant. This whole thing of 'You have to get help in.' but nearly as soon as that happened, the public health nurse kind of said 'Oh well that situation is sorted.'. (P18)

For 2 women in the intellectual disability strand this perception of being judged became an actual reality when the option of fostering their babies was presented to them in late pregnancy, by the social worker.

'[They first told me they would take the baby] near the end of the pregnancy. About 3 or 4 days before I went into labour... I was awful upset, they wouldn't let me keep her like and bring her home'. (ID3)

'... and he [social worker] was saying to me I wasn't going to be allowed keep this baby and I was nearly due to have the baby... I feel that he shouldn't have said that to me ... Because... I felt very unwell from it, I was crying and very upset... he said I wouldn't be able to mind her and I am able to mind her. I'm well able to mind her.. (ID2)

Another woman in the intellectual disability strand of the study provided a vivid description of what it felt like to be constantly watched and observed while interacting with her baby. The baby was in foster care and arranged visits were scheduled with her, the birth mother. The woman's interactions with her son were video recorded and then reflected on as a means of helping her with her parenting skills but she felt threatened by the video:

'I want [baby] back and I just want the social workers to go out of my life because they just make my life hell and I've never had one day without them with [baby] they're always sitting there watching me and of course then I had the lady, another lady with a camera ... she used to come in, take 10 minutes of a little video and then she'd show it to me and she'd give me pointers and tell me things that I'm doing wrong...'. (ID1)

This fear of being judged, observed and watched continued when the women went home:

'I actually saw her [PHN]; she just came along when she wanted to catch you out or something. I think that's what they do. She was just kind of trying to provide extra support or trying to keep an extra eye on me, you don't know whether she was just checking up on me.' (P2)

"Now I felt very intimidated by her. She [PHN] came in like and she said 'Oh I just want you to do this thing 'til we see how you're getting on with your child.' and I felt, she kept watching me, watching me, while I was doing it and I felt very uneasy when I was trying to fill in the questionnaire [EPDS] so I put down on it what I thought she'd want me to put down.' (M13)

This feeling of being observed and watched was not experienced by all women. A small minority of women did find the health professionals very helpful and supportive of them in their parenting role.

'I never got the feeling they were watching me, I always got the feeling they were always there to help me'. (V11)

The fear of losing custody of their baby was *'a terrible fear'* (M14), felt by most of the women experiencing mental health difficulties or an intellectual disability, and some of the women from other strands of the study.

'I ... remember going to my psychiatrist at one point and saying to him, I'm just, I'm worried that I'm getting sick again and if I do, are they going to take [baby's name] off me'. (M18)

'Yeah all along what was going to happen, like that they would take them [children] off me'. (M16)

I [was] scared of [the] social worker coming down the house ... scared. I think myself, maybe the social worker may take the baby away' (ID4)

'Just the time when I was having suicidal thoughts and thinking about harming the baby. Just when I left [the psychiatrist] then it occurred to me then that, what if she reports me and they take the baby off me for my own good? I did worry about that and I regretted telling her'. (M3)

'I was afraid if I did anything wrong the child would be taken off me, that's what I was afraid of most'. (P12)

'This woman [midwife in maternity unit] pulled my mother aside ... and basically said 'Your daughter is not fit to look after this baby. This baby is going to end up being taken away by social services.' la-di-dah and my mother freaked out'. (P7)

For women in the intellectual disability strand of the study the loss of custody became an actual reality. One mother had her baby placed into foster care immediately after the birth but was able to take over her care again after she was relocated in supported accommodation. Even when her baby was returned to her, the threat of loss of custody remained.

'They [social workers] want me to live up here [supported accommodation] but I don't want to live up here ... they said if I leave

this place like I'll get her taken off me again. So I'll have to stay here with her'. (ID3)

The baby of another mother with an intellectual disability was placed into foster care and remains there to the present day. In this case fostering was discussed with the woman in the early postnatal period.

'[Fostering issues came up] at the start ... my social worker [brought it up]. I suppose I was more scared of whether I could look after him or not, but I felt after I had him I knew I wanted him... but they didn't think I was ready or I could cope'. (ID1)

Foster care was also suggested to one woman with a history of depression.

'She [PHN] thought well, this person is depressed and this [foster care] is what she needs. I was nearly ... worse then with that suggestion. .. a couple of days later my nurse [mental health nurse] came back and she said 'Oh I wouldn't consider that.''. (M16)

A number of women described how they put on a 'front' for fear of being judged an unfit mother and having their child taken from them.

'I had to put on this whole front. The house was perfect anytime anyone came and that [baby's name] was perfect any time anyone came and everything was great or I was going to lose him...From inside me and there was this voice that just kept saying over and over, 'If you tell anyone you'll lose him'. That was just making it worse'. (M4)

'My GP... did send me in to [name support midwife] at one stage but...I played down how bad I was feeling ... I thought they were going to take my baby off me or something, so I went in, put a bit of make-up on and I kind of played down how I was feeling'. (M8)

5.4. Health professionals' knowledge and understanding about disability or impairment

5.4.1. Health professionals' lack of knowledge

The women recalled how health professionals lacked knowledge and understanding about their disability or impairment.

'The physiotherapist, I was asking her questions, how will it affect the legs and the back ... and her answer to me was kind of like 'Well, I know as much about it [cerebral palsy] as you do.' (P7)

'From day one, with the MS she [GP] said 'Look, I know nothing about it.' ...she didn't even know the drugs...she had to look them up. (P10)

'I found they [health professional] were very ignorant to the eye condition, they would constantly ask me questions about my eyesight and why my eyes moved etc.. Furthermore no one once ever asked me ... if this disease could be carried on into the next generation'. (V3)

'He [GP] doesn't know much about [eye problem], he'd have to read up on it, about the genetics of it ... which I thought was actually quite nice ...he would gone through the effort and would have read up on it'. (V1)

For one woman in the physical disability strand the physiotherapist called to her home during pregnancy and was instructing her on the correct way to do her pelvic floor exercises:

'She [physiotherapist] ... was coming out [to the house] and I was still pregnant and trying to get me to do all these pelvic exercises, and if I said it to her once, I said it to her a million times, 'I cannot do this, I'm a person with a disability. You need to either give me an exercise that I can do in an alternative way, I can't do these' '. (P18)

The physiotherapist's lack of knowledge, coupled with a lack of understanding on the public health nurse's (PHN) behalf also, impacted on the woman's experiences of the early postnatal period and her transition to motherhood.

'I was fuming, I was really, really upset ... I just said '[husband's name], I said, I want all these people out of my house. Number one they're coming into my house and they're dictating to me.' I said 'I don't want anything to do with her [PHN] anymore'..., without doubt what should be the happiest time in your life was the worst 3 months of my life, it was just hell and it was complete lack of understanding'. (P18)

Some health professionals did acknowledge and recognise the woman's expertise in relation to her disability or impairment and would often refer to her if they had any queries.

'I had to tell them [health professionals about the disability]. I think in a way it's better because if they already have ideas they might have preconceptions that are not correct, so I think it was in a way better because it meant that I was the expert'. (P5)

However, not all of the women embraced this perception of them being the expert.

'It felt very awkward in a way to be telling health professionals about my disease, when a) they should have known about it, and b) they should have known what it was'. (P3)

'I'm tired of telling them [health professionals] 'I'm deaf.' ... you have to do it all over again and again and again'. (H8)

5.4.2. Lack of recognition of postnatal mental health problems by midwives

The women interviewed, both those who developed postnatal depression with no previous underlying disorder and those who had previous mental health difficulties, did not expect to experience postnatal mental health problems. It had not been discussed prior to birth, and information had not been given about the possibility of experiencing any mental health problem. In the postnatal period there did not appear to be a willingness on behalf of midwives to engage with the women to explore their distress and difficulties. Consequently, early signs of distress were missed.

'I just wouldn't hold the baby at all. I had the curtains closed ... the nurses kept pulling the curtains around and saying 'Come on, up, have your breakfast.' and I was like, I didn't want to eat, I didn't want to... Not one of them mentioned postnatal depression... I didn't know what was happening ... I didn't think I'd ever experience postnatal depression because I'd wanted the baby so much ... then we got home, the first thing I done was hand the baby straight over to my partner and I just went upstairs and locked myself in the room and cried solid for 4 hours'. (M14)

'After the [caesarean section] ... well to me it was like the postnatal depression just hit me as soon as they took [baby's name] out and that whole time in the hospital I got no support... they didn't notice'. (M13)

5.4.3. Lack of understanding of mental health difficulties

Women with mental health difficulties spoke of the lack of understanding that others had of their distress.

'I mean how do you sit down and say to somebody 'I feel miserable and awful and horrible'. And then they, you know, just generally sitting here going 'But sure how, why, like I mean look at what you've got and 3 beautiful children.''. (M7)

'Yeah, but as he [psychiatrist] said 'Unless people can see, if you've broken your arm, you don't get a lot of sympathy.' ...and it's still quite a closed subject, people don't like to discuss it, it's like...they're going to think I'm mental or you know, 'Off the wall, it's all in your head.''. (M9)

Because of this lack of understanding, there was a lack of acceptability and a sense of stigma around mental health difficulties.

'Yeah, it's the whole stigma my family put on, because I was always the strong one in the family, the happy and the bubbly one, the one who kept everyone going, they couldn't ...handle the fact that I wasn't right, and none of them helped me, my mam and dad did in their own way, but not the way they should have basically'. (M8)

'It's just something I wouldn't talk openly about that I do come here [mental health resource centre], but I don't know why I don't.' (M12)

'My husband knows and that's it. You know, I don't tell anybody else because they don't understand.' (M6)

'I ... had to ask [health insurance company] was my policy covered for cognitive therapy and you kind of think 'are they judging me?' ' (M4)

For some women the shame of having a mental health problem became a self stigma, and women judged themselves very harshly.

'No, I'm mortally embarrassed about it [mental health difficulties], it's a horrible thing, it's a huge, huge weakness, you don't want to go around telling everybody or anyone actually, it's just not something that I would talk about'. (M15 (3rd interview))

Women's feelings of worthlessness were reinforced by their repeated lack of access to appropriate services, despite their requests. Consequently, as this

woman's quote demonstrates, women began to feel that they were not deserving of a quality maternity or mental health service.

'When you have to ask repeatedly for something ... it kind of makes you feel like you've had to fight for it because people begrudge it you, and they begrudge you because you don't deserve it...so it is quite uncomfortable and it's a very shameful subject in a way, it's very difficult to ask'. (M15 (3rd interview))

5.5. Conclusion

In this theme of acceptability and attitudes the women's experiences of establishing an interpersonal relationship with health professionals was presented. The majority of interpersonal relationships with health professionals were positive. However, the findings illustrate the challenges that women with disabilities encountered when communicating and interacting with health professionals. The basis of such difficulty emanated from the attitudes exhibited by some health professionals who were described as paternalistic and patronising. Some women found that the communication by health professionals around screening their babies for inherited disorders was handled in a very insensitive and judgemental way.

Women emphasised the importance of building a rapport with their carers and appreciated being treated the same way as other women. The majority were complimentary about the care received from midwives in the labour ward, but relationships in the postnatal area were not as good. In particular, midwives were described as rushed and too busy to provide psychological or emotional care. The majority of women were pleased with the relationship with their public health nurse, although a substantial minority described them as uninterested, inconsiderate and inflexible. Relationships with other health professionals were mixed.

Communication with health professionals was difficult for those with sensory impairments, and this impacted on the level of trust between women and their carers. The overarching issue was the lack of knowledge and understanding

of the woman's disability or impairment, particularly in relation to postnatal depression and other mental health difficulties. This lack of knowledge and understanding led to a perception that health professionals were insensitive and lacked empathy, which had a demoralising effect on women with disabilities.

One compelling finding was the women's fear of losing custody of their baby, especially for women interviewed in this study who had an intellectual disability or who experienced mental health problems. This was accompanied by a perception that health professionals were constantly observing, watching and scrutinising their ability to parent and to execute parenting skills as prescribed by a non-disabled society.

Chapter 6 Findings from interviews with women

Theme Five: Affordability

6.1. Introduction

The theme affordability refers to whether or not women can afford the health services on offer. None of the women expressed any concern over the cost of maternity services, probably because of the existence of the Maternity and Infant Scheme, which provides a free programme of care for expectant women and new mothers resident in Ireland. It provides for care to be shared during pregnancy, childbirth and the early postnatal period between the woman's general practitioner (GP) and hospital-based obstetrician. The provisions of the scheme set out that the GP provides an initial examination, before 12 weeks if possible, and a further 6 examinations during the woman's pregnancy, which are alternated with visits to the maternity unit. This schedule of visits may be changed by either the GP and/or hospital obstetrician depending on the woman's individual situation. If the woman has a significant illness, such as diabetes or hypertension, an additional 5 visits to the GP may occur. The scheme also prescribes that in the early postnatal period the GP will examine the baby at 2 weeks and both the mother and baby at 6 weeks. Other costs incurred in accessing services, such as transport, and using additional services, however, did cause concern to some women.

6.2. Transport costs

Women in the physical, sensory and intellectual disability strand of the study discussed the issue of cost under the subject of getting to and from the maternity unit for antenatal visits or parent education classes.

For a small minority of women taking public transport was very costly.

'I'd usually take the train to [name of city] with my mum and get a taxi to the [name of maternity unit]. The ticket would be about 15 euros return and then the taxi would be another, I suppose, 10 or 15 on top of it'. (P4)

'I can't drive and if you had to travel out of town you would have to get taxis, well you wouldn't be able to afford them'. (V7)

'I'd take a taxi, it was expensive ...I spent an awful lot of money going back and forth to the doctors and the hospital'. (H17)

6.3. Costs of additional services

As previously noted, one woman with a hearing impairment (section 3.4 (H11)) described how she was told she would have to supply and pay for her own translator in order to access antenatal classes. One woman in the physical disability strand, with a twin pregnancy, said that her GP sent a referral letter to the maternity unit and requested an urgent appointment and scan to ensure the fetuses had no adverse affects from the medication the woman was taking for her disability. The woman was given an appointment at 16 weeks gestation, but the GP considered this too late so, worried about her babies, she decided to have a scan in a private clinic at her own expense.

'I was given an appointment for 16 weeks, despite ringing, me ringing and my doctor ringing, they [maternity unit] said 'That's considered an urgent appointment'. So I had to go and pay to get a scan done in the [name of private clinic] at 8 weeks to make sure that everything was okay'. (P17)

Another woman in the mental health strand, because of her age, wished to have a scan before 16 weeks gestation. The only way that this was possible was to pay for it herself.

'Well when I found out I was pregnant ...I found it extremely hard to get an appointment to get a scan... I couldn't go publicly... every appointment I got was too far in advance so I ended up going private and I still had to ring loads of different obstetricians to see would they take me on, you know'.(M1)

Two women in the physical disability strand had hoped to have a home birth and retained the services of an independent midwife. They received their antenatal care from the independent midwife but complications arose during pregnancy, which prevented them from having a home birth; however the women still retained the services of the independent midwife, at a cost to themselves, for the early motherhood period.

'The midwife who I'd been seeing for the home birth came to see me [in woman's own home] every day and she was fantastic, she'd stay for maybe an hour and checked that everything was fine'. (P11)

'Once I got home things did normalise a lot because I still had the [home birth] midwife come to me maybe twice a week or even more often for the remaining 4 or 5 weeks'. (P3)

In the absence of psychological therapies within the maternity services and the mental health services, some women in the mental health strand reported seeking help for their mental health problems from private services, which proved to be very expensive and not sustainable for many of the women. Women paid for a range of services, including cognitive behaviour therapy, acupuncture and hypnotherapy.

'I had to pay for that myself she [counsellor] was 50 or 60 euros an hour and [Cognitive Behaviour Therapist (CBT)] was 150 euros a go. He [CBT therapist] was big money so that was a big drain on us ... 300 a month, which was a lot. And I know I had that thing where you only pay 85 euros [medication] so we were paying that as well ...but [therapist's name] was very expensive 300 euros a go and you can't claim it back on [health insurance company] either'. (M4)

'I mean I spent out 100's of euros for different treatments and out of my own pocket, you know. In fairness now the acupuncture and that I did get refunded on but the likes of hypnotherapy and the cognitive behaviour therapy, the cognitive behaviour therapy was 70 euros a session...It's a lot of money and when you're going every week'. (M9)

'Acupuncture I think it is a very powerful alternative therapy but you have to go every single week and it was costing 50 euros for the acupuncture and they would always give me another herbal and that was another 15...I couldn't sustain that, you know ... I even went to, what do you call it, cognitive therapy. I've spent lots of money; I've spent an absolute fortune'. (M1)

'There is no psychological support whatsoever, so I sourced my own ... in an ideal world I'd like to go back and get the support that I need from there [mental health service] in a non-judgemental environment, but that's not going to happen so the next best thing is to pay for it myself, which is hard but it will provide a better service so I get my cognitive behaviour therapy, which I need. And that's what I'm doing'. (M10)

6.4. Conclusion

Affordability only emerged as an issue for a minority of women interviewed, partly because of the existence of the Maternity and Infant Care Scheme, which stipulates that women resident in Ireland receive free care during pregnancy, childbirth and early motherhood. It should be noted, however, that only 3 women in the sample gave their occupation as unemployed, which would have a bearing on these findings. Some women had to pay substantial amounts to travel to their appointments in the antenatal or postnatal periods. Women in the mental health strand incurred the cost of additional services, particularly psychological therapies and support. For others the benefit and ease of mind afforded by an early scan, which the women perceived the maternity services could not facilitate, out-weighed the cost of the scan. The women seemed resigned to the fact that they would have to incur these additional costs and although they remarked on how expensive things were, this theme did not generate as many responses as the other themes in the study.

Chapter 7 Findings from focus group interviews

7.1. Introduction

In addition to the individual face-to-face interviews with women with disabilities, health professionals from relevant disciplines were invited to participate in one of 6 focus group discussions relating to the provision of services for women with disabilities accessing the publicly-funded health services during pregnancy, childbirth and early motherhood.

The aims of the focus groups were:

- a) to ascertain the views of health professionals on the quality of current service provision for women with disabilities and
- b) to identify how future services can meet the needs of women with disabilities.

Multidisciplinary focus groups were conducted in 4 different regions – Dublin, Donegal, Galway and Waterford. Health professionals including midwives, obstetricians, general practitioners, paediatricians, neonatologists, public health nurses, social workers, physiotherapists, psychiatrists, mental health specialists and maternity care assistants were invited to participate in a focus group located near their place of employment.

The Health Service Executive's local health offices in each county were contacted and they provided the contact details for the general practitioners, public health nurses, social workers and physiotherapists employed in the primary community care services. Letters of invitation were also sent to health professionals working in the 19 publicly-funded maternity units. Over 600 letters of invitation were posted. In addition, health professionals working in a specific mental health service and in intellectual disability service providers from voluntary organisations affiliated to the Federation of Voluntary Bodies of

Ireland (FEDVOL) were also invited to participate in 2 disability specific focus groups.

7.2. Participant demographics

Thirty people participated in the 6 focus group discussions. Four focus groups comprised of a variety of professionals where the focus was on all 5 disability strands of the study, while the remaining 2 focus groups were disability specific; one focused specifically on mental health issues and the other on intellectual disability services. The focus group regarding mental health issues arose because the health professionals involved were unable to attend the multidisciplinary group scheduled for their area, but were very eager to contribute their views (Appendix 2, section 4.7.). The focus group specifically for service providers from voluntary organisations affiliated to FEDVOL was convened to discuss issues relating to women with intellectual disability only (Appendix 2, section 4.10.).

The focus groups held in the Leinster region had the largest number of participants (n=17, 57% (includes the intellectual disability focus group (4), and telephone and email responses (4)); in Ulster there were 9 (30%) (includes mental health specific group (3)); in Connacht 2 (7%); and there were 2 (7%) participants in Munster (Table 6).

Table 6 Participants in focus group

Region	Number of Participants	Percentage
Leinster	17	57%
Ulster	9	30%
Connacht	2	7%
Munster	2	7%
Total n=30		

Eight disciplines/ sectors were represented including midwifery (n=10, 33%), the largest single group represented, nursing (n=3, 10%), mental health

specialists (mental health nurses and midwifery specialist) (n=4, 13%), intellectual disability service providers (n=4, 13%), social workers (n=2, 7%), physiotherapists (n=2, 7%) maternity care assistants (n=3, 10%) and medicine (n=2, 7%) (Appendix 2, Table 7). The majority (n=20, 67%) were working in hospital settings and 33% (n=10) worked in the community. The findings of the focus group with intellectual disability service providers are presented separately after those of the other groups.

7.3. Findings - health professional groups

7.3.1. Framework guiding focus group discussions

Four questions were used as a framework for the focus group discussions with health professionals:

1. What from your [health professional's] professional perspective are the important needs of women from each of the different strands of the study [physical disability, hearing impairment, vision impairment, mental health and intellectual disability] during pregnancy, childbirth and early motherhood?
2. What are your views on the quality of the services currently available to meet the needs of women and their families from all 5 strands of the study?
3. What are the greatest challenges in delivering services for women and their families from all 5 strands of the study?
4. How can these challenges be addressed?

The responses to these questions were categorised under 3 of the themes identified in the literature review and interviews with women, namely:

accessibility, accommodation, and acceptability. Availability and affordability as themes did not emerge from these discussions.

The participants' words are used to illustrate the themes and categories identified. Words inserted in brackets thus [], are the researchers' additions to increase clarity. Words omitted from a direct transcript are indicated by 3 ellipses thus (...). Identifiers are included after each quotation; (FG1) indicates the first interview undertaken and so on.

7.3.2. Accessibility needs of women with disabilities during pregnancy, childbirth and early motherhood

7.3.2.1. Accessibility needs of women with a physical disability

In relation to women with a physical disability, issues around accessibility to the physical environment, forward planning, support and assistance dominated the focus group discussions. Many of the key points to arise were similar to those identified by the women in their interviews.

'The key is access to and from the hospital, safety and transport to and from the hospital'. (FG1)

'Good physical access to the services so they [women with disabilities] need no barriers. Getting people into the hospital, getting them parked up'. (FG2)

Access into and within the maternity unit and health centres were also considered. Participants identified how the provision of a ramp and automatic doors would reduce difficulties for women with a physical disability or visual impairment when accessing the various departments in the maternity unit/hospital.

'Anywhere else in the maternity unit access for anybody with a wheelchair would be good, but at the [antenatal] clinic... all the rooms are actually up steps, ... it's a very old, old building... there is a consulting room that is at ground level and the [midwives] use that so

the ladies [with a physical disability] go there and the doctors come down to that room'. (FG4)

'[In] the early pregnancy assessment unit there is steps ... it is inaccessible for women with a physical disability and we [maternity unit] need to address that'. (FG1)

The majority of maternity units/hospitals appear to have accessible equipment but the participants spoke of challenges that are encountered by women with physical disabilities when trying to gain access to and navigating the interior environment of some units.

'Access within the maternity department is good because everything is... wheelchair-accessible, we have beds that go up and down, [but] we don't have cots that go up and down. It may be difficult to get into the bath but we do have showers that are accessible and she [the woman] can sit under the big shower ... everything is on wheels except the midwives'. (FG4)

'We have adjustable beds and equipment. On the postnatal ward there is a bathroom that is accessible ...there is enough space for a wheelchair'. (FG1)

'[We] do have a bathroom that may not be suitable, there are high steps into the shower'. (FG1)

Participants spoke of how some maternity units/hospital are old and because of the external and internal architecture some key departments are inaccessible.

'Lots of our buildings [maternity units] are old buildings so there are steps everywhere, ramps are available but they aren't accessible unless [the woman] gets assistance from somebody like the security or portering staff to come ...the doors are too narrow so even if [the woman] gets into the department she cannot get into the office and that is very difficult'. (FG1)

A purpose-built wheelchair-accessible room is available in some units.

'We have a purpose-built room, a 2-bedded ward that is wheelchair-accessible and we have wheelchair-accessible toilets in a number of areas ... and height adjustable beds and the doors are wide'. (FG1)

7.3.2.2. Accessibility needs of women with a vision impairment

Regarding the needs of women with a vision impairment, 2 points dominated the discussions, namely access to the structural environment and forward planning. Gaining access to the maternity unit/hospital and orientation to the physical environment was considered important. Participants spoke of how all staff must have some awareness of the importance of orientating the woman to her environment and keeping the environment uncluttered and barrier-free.

'[Midwives] need to point to where everything is in the room so that she [woman] knows actually how many steps she has to take and when her meals are brought in they are actually put beside her and it just makes things easier for her, she knows ... where everything is... an awareness of staff to make sure that things are not moved in the room'. (FG1)

'Getting her [woman] to walk the route and getting ... her familiar with the surroundings'. (FG3)

'We [maternity care assistant] would be there to help them, keep an eye on them ... support them. The ward is so big but you would always have in the back of your mind an awareness that they are there'. (FG4)

'If the woman was to come in... a 6-bedded room would be quite daunting, people are constantly moving chairs, beds and tables and things like that. A single room where she would become familiar with the shape of the room would be better'. (FG4)

Policies and procedures need to be flexible to accommodate the woman if she chooses to have a companion with her.

'Orientation would be difficult if ... they have no sight at all. If a carer wants to stay with them [woman] we would probably accommodate that...we do have people stay if there is problems'. (FG4)

7.3.3. Accommodation needs of women with disabilities during pregnancy, childbirth and early motherhood

7.3.3.1. Accommodation needs of women with disabilities

Participants discussed how health professionals should accommodate to the needs common to all women with a disability. First they identified how health professionals should determine what the disability is:

'The number one issue is to see what disability [the woman has]'. (FG1)

Secondly, they felt that each woman should have an individual assessment of needs and an appropriate plan of care developed at the first antenatal booking visit. To facilitate the development of this plan an early appointment and review is necessary. The woman, the multidisciplinary team, and the woman's support person(s) should be involved in planning the woman's care. Interdisciplinary collaboration is necessary and the women may require a referral to other professionals depending on their specific needs.

'[In] the antenatal clinic it [woman's needs] would be identified clarified and a plan put in place'. (FG1)

'A plan of care from the very, very start a definite plan of how you [health professionals] would like things to proceed and how you would like things to evolve and that means involving all the persons involved in that person's life be it the GP, be it the family, be it professional carer whoever that may be so that an individual care plan regardless of the disability [can be developed]'. (FG2)

'Acknowledge or identify women when they're booking in, in relation to their needs and social work involvement'. (FG3)

'There is essentially an individualised care plan done at that stage[antenatal booking visit] so any disabilities or any difficulties that this woman foresee [are identified]'. (FG4)

They emphasised that health professionals need to facilitate and maintain effective communication with the woman, be aware of her expectations, and determine a plan for birth so that essential equipment can be sourced in time.

'[Issues] clarified and planned beforehand so that plans would be clear and depending on the plan and what's in the plan equipment ... would be brought in beforehand to help her'. (FG1)

Participants discussed how good communication is essential. Health professionals need to be aware of the value of the spoken word and to be respectful, empathetic and sensitive when interacting with women with disabilities. Participants discussed how current professional registration,

education and training programmes provide some awareness of disability issues and the generic needs of women with disabilities.

'Keeping the communication going on [is important]'. (FG1)

'The priority is communication'. (FG1)

'There is education programmes [both in midwifery and maternity care assistants] in relation to disability and creating awareness to look at the needs of a mother that have particular problems'. (FG1)

Participants acknowledged the importance of creating collaborative links with other maternity units and general hospitals. Linking with clinical specialists in other areas including the mental health and intellectual disability sectors is necessary. Health professionals need to adopt a multidisciplinary approach from the very outset. This approach should be implemented when the woman first accesses health services during pregnancy, which would facilitate the identification of the woman's specific needs and the mobilisation of resources and services to meet such needs.

'If needed we [maternity unit] would find the resources. Where resources are needed we would make every effort to put in additional resources and you may not be able to guarantee it around the clock but you would try and do your best'. (FG1)

'We [midwives] have very good links with [names of 2 general hospitals] and if there are any issues we link with the clinical specialists in the area and we have done that on some occasions when there are certain things we need information on'. (FG1)

'[We use] the greater multidisciplinary team that are available to us [midwives] in the hospital like OT [occupational therapist] or physio [physiotherapist]. We work very closely with the community welfare officers and the social welfare services'. (FG2)

Participants discussed the need for health professionals to acknowledge the woman's individual needs and the importance of gaining informed consent. There was a consensus that for women with either an intellectual disability or mental health difficulties health professionals appear to be more aware of the need to gain informed consent from this population.

'A lot of women don't have a lot of choice anyway ... but it's funny, the intellectual disabilities probably do better in terms of choice than the mainstream group because people are more conscious of having consent with them...people are quite conscious that one needs ... to explain this really well and ...make sure that they understand'. (FG3)

'With the mental health group we [midwives] are more aware that we have to make damn sure that we're able to say we got consent, it's more of an issue for us with this group, we're better at it with this group than we are with the general population'. (FG3)

Some participants also highlighted the importance of *'not stigmatising or marginalising'* (FG5) women just because they have a disability. They believed that health professionals must respect the woman's right to the same health services provided to any woman during pregnancy, childbirth and early motherhood.

'[It's important] you [health professionals] don't stigmatise but you might have to look at the fact that this woman may be in a wheelchair and she may need a special way of bathing the baby so again, individualised care'. (FG2)

'Respect for everyone's rights and the right to the same services is important'. (FG2)

'It's our attitudes sometimes, you have to guard it [attitude] in speaking to the person and not to the person with them, you need to be conscious of it and how we approach people'. (FG1)

Linking with voluntary agencies was considered important.

'We would discuss [with women] in the antenatal clinic and then if there is something needed we would follow up on it. Follow up with voluntary agencies is hugely important and there is links with them'. (FG1)

When addressing the woman's specific needs, these health professionals stated that they should be creative with existing resources and flexible with policies, procedures and guidelines. Participants believed that a person-centred approach should be adopted when planning care antenatally, intranatally and postnatally.

'Using the resources that you [maternity unit] have and just extending them a little bit. [In] the ETH [Early Transfer Home⁶ services], we had a lady who did not fit the criteria for ETH and stayed her 3 days in hospital to learn the additional care ... but we did extend the criteria and the ETH did take her when she went home to give her the additional support she needed'. (FG1)

'If women could have their care at home like the DOMINO or something they could avoid that awful place [maternity unit]'. (FG1)

Health professionals need to incorporate the women's disability, acknowledge and recognise the woman's innate ability to adapt and cope when preparing for or performing parenting skills. Participants believed that women with disabilities might need one-to-one parent education classes, which should be facilitated.

'Antenatal education is very important ... [it] can be done in a one-to-one class'. (FG1)

7.3.3.2. Accommodation needs of women with a physical disability

A particular point of discussion around the perceived needs of women with a physical disability was support and assistance. Participants identified how women may need a companion of choice to accompany them while in the maternity unit/hospital. Women may need support and assistance with the practical aspects of baby care. Practical tools and/or aids, should be sourced and made available to assist women in their parenting role.

'Practical aspects of baby care depending on what the mother needs ...if there are tools or aids which would empower her [mother] to attend her baby'. (FG1)

'When she [woman] goes home, the home may not be designed for baby in mind she may need assistance and additional help in terms of additional amendments to her overall environment'. (FG1)

⁶ The Early Transfer Home (ETH) scheme is implemented in the majority of large maternity hospitals in Ireland. Women who meet certain criteria of normality are, with their consent, transferred to the care of the ETH team. A midwife from the team assess the woman's needs, she and her baby return home within 24 hours of the birth, and are visited by a team midwife daily for (usually) 2-5 days.

Women with a physical disability may not be known to the public health nurse, who also may not be aware the woman has become a parent until they receive some correspondence from the maternity unit.

'Antenatal mothers with a physical disability may not be necessarily known to the public health nurse in the antenatal period, there is a gap in terms of preparation. As regard the postnatal public health nurse services we would often not know that this particular family were expecting a baby until we hear from the postnatal ward'. (FG4)

'[The] public health nurses visit and do the postnatal checks in the woman's home, which will be adapted for her needs as required, and do the care in her own environment which is adapted and usually the mum is very independent in her own environment and self-caring'. (FG4)

7.3.3.3. Accommodation needs of women with a vision impairment

When addressing the information needs of women with a vision impairment, the participants identified the need for one-to-one antenatal education classes and an appropriate means to disseminate information.

'They [parent education] don't have tapes or CDs but they can be sourced and accessed if necessary'. (FG1)

'... it is a good idea[to have information in Braille], it would be a fantastic idea if you happen to be visually impaired, but the financial cost of it is prohibitive'. (FG3)

'The antenatal class provided ... by the public health nurse in rural health centres, there may be a possibility of having difficulty accessing the classes or even knowing the classes are on because the classes are advertised by flyers'. (FG4)

A public health nurse (PHN) identified the importance of linking with the community social worker and other organisations and agencies in relation to infant/child development and parenting of the toddler:

'The needs change as the toddler grows ... so we [PHNs] would often link with other agencies to support and promote independence of the parents and allow the stimulation and development of the toddler'. (FG4)

7.3.3.4. Accommodation needs of women with a hearing impairment

Participants identified how communication is a priority for women with a hearing impairment.

'[For] a woman who was deaf but could lip read, [health professionals] should ensure to position themselves so that the woman can lip read what was being said'. (FG1)

Participants stated that during any interaction with the woman, health professionals should not ask relatives to act as an interpreter. The services of an impartial third person, a sign language interpreter should be engaged. A small number of maternity units have midwives who have received some training in sign language; however, this is not the case in the majority of units.

'We've trained our midwives in sign language. They keep their skills up, they meet once a month and sign away'. (FG3)

'We [maternity unit] have a number of people who speak Polish, Arabic, Irish, Indian and but signing I don't know anyone on the staff who can do signing'. (FG4)

'[A] major concern was how ... to communicate with the hospital, we [maternity unit] were thinking how would we do it and actually we use the mobile phone, we text everything and it's great, [women with a hearing impairment] could text in and the midwives used to text out ... so you have to think of ways'. (FG3)

Participants noted that information should be provided in an accessible and appropriate format, which is important if decision making and informed choice are to be facilitated. Women with a hearing impairment may need one-to-one antenatal education classes. In some regions engaging the services of a sign language interpreter was said to be difficult.

'[Name of antenatal educator] organised an individual antenatal class for them [women with a hearing impairment], a one-to-two with a sign language interpreter. [The] biggest problem would be accessing an interpreter if the woman has nobody with them, the vast majority of these women if they are severely impaired can lip read to some extent but actually getting hold of an interpreter is difficult ... it's usually ...organised through the social work department and the Irish Deaf Society'. (FG4)

Participants advocated for support and pointed out that the assessment process should consider the whole family unit i.e. if just the mother or both parents are deaf.

'Parents should be given equity and fairness and a lot of support on site and then the assessment very much will depend on the family unit'. (FG4)

Participants were of the view that community-based health service providers needed to collaborate and link with voluntary organisations and agencies.

'In the community we [PHN] would work quite a lot with DeafHear and they have sent people out with sign language with the PHN'. (FG4)

'[The] community social worker department and DeafHear will give you everything and anything as regards person, manpower and equipment and it's great if the link is there antenatally between the maternity unit, parent, and the public health nurse'. (FG4)

A multidisciplinary team approach was said to be vital and should be developed in the antenatal period.

'It's important that we work together as a team, like the social work department, occupational health, midwives, the maternity care assistant as a holistic approach'. (FG1)

7.3.3.5. Accommodation needs of women with an intellectual disability

Participants in the focus groups suggested that the needs of women with an intellectual disability were more complex and difficult than any of the other populations. They suggested that assessment for this cohort can be difficult depending on the degree of disability. There may be serious difficulties around issues of understanding and consent to treatment.

'We [social worker] have had serious difficulties [with women with an intellectual disability] and I'm sure some patients have had difficulties with us around ... issues like ... understanding, consent to treatment'. (FG1)

'Sometimes how they [women] act can be a problem ... it's [intellectual disability] not always disclosed, it's sort of an impression or an assessment [midwives make] and that can be a little bit difficult'. (FG3)

Assessing the woman's ability to parent and the potential of loss of custody can be a stressful and traumatic experience for all involved including the woman and health professionals.

'If the baby is going to be taken from the care of the mother for any reason ... that's all stress ... [it] can be extremely traumatic for the patient as well as for people working with her'. (FG1)

Participants discussed how antenatal education for this cohort needed to be facilitated by persons working or associated with the maternity unit.

'Antenatal preparation and understanding [is important], a lot of people have key workers from other services that they attend and they seem to be doing more and more of that prep work which ... would be better done in the maternity unit'. (FG1)

However, key workers and family need to be involved in the planning of ongoing care for the woman. Establishing a trusting relationship is paramount.

'[For women with an] intellectual disability, you might need more family involvement'. (FG2)

'We [midwives] do ask the normal questions but we don't ask too many probing questions, we wait to build up a relationship, trust and whatever and then people just disclose'. (FG3)

Again a multidisciplinary approach and linking with voluntary organisations and agencies were highlighted. The care plan when formulated should be communicated to all members of the multidisciplinary team and documented clearly and accurately in the woman's case notes.

'Good antenatal assessment and a good plan put in place it makes things so much easier ... written communication and documented on charts'. (FG1)

'Maybe lay support, voluntary support ... they don't necessarily need more midwifery or clinical midwifery input, they need to be able to access some maternity assistance'. (FG3)

'From a midwifery point of view, the physiological and actual physical support is good, midwives are very focused on one-to-one care and psychological support and always involve the maternity care assistant'. (FG4)

Participants spoke of how parent education classes may need to be arranged on a one-to-one basis at the correct level and how maternity units may need to be flexible with policies and procedures.

'The most difficult thing for us [midwives] is pitching the information and teaching at the right level'. (FG4)

'We [midwives] always do a one-to-one [antenatal class] and their carer comes with them and you [midwives] get their level of understanding'. (FG3)

'Sometimes the main carer might be a family member who wishes to be with her [woman] while in hospital and we do our best to give them a room that they will be comfortable in'. (FG1)

The focus group discussions highlighted the lack of support outside the maternity unit for women with an intellectual disability. The deliberations also highlighted how much support is needed for parents and family of the woman with an intellectual disability.

'Often the support needed is for the parents of the intellectual disability girl who became pregnant. A lot of support is family acceptance and then ... letting them [woman with intellectual disability] know and understand what's happening and it can be quite frightening they don't know what's happening to their body and it's very difficult to communicate'. (FG4)

'The lack of support outside the hospital is an issue ... there needs to be some kind of supported accommodation and it's not just for intellectual disability but other disabilities too, just to get enough time to build up the skills and the confidence sometimes just to be able to move on'. (FG1)

'There would be social worker involvement in most cases and social worker awareness certainly ... if these mums need to stay in longer while learning child care and parentcraft skills that sort of thing the maternity care assistant going over and over things like bathing, more time is given to them ... we can bend the rules for them and it's

individual, the maternity care assistants will do a lot of one-to-one on personal care'. (FG4)

Again the discussions highlighted how health professionals need to build good relationships and links with voluntary organisations and agencies in the community.

'Women with additional needs would be referred to ... a house or home [in the community] for people who need support in and around their pregnancy and they would stay there until the baby would be maybe, oh a good few months old, maybe even up to a year'. (FG3)

7.3.3.6. Accommodation needs of women with mental health difficulties

In relation to women with mental health difficulties, participants discussed issues around disclosure of the illness, the importance of developing a plan of care in the antenatal period and having an agreed mechanism of referral. Participants emphasised the sensitivity needed and the importance of links with mental health specialist services, where such services exist.

'There's a lot of stigma about mental health ... that comes back to the antenatal period at the antenatal booking visits how it's sold, how the services are sold, how the questions are asked you [all health professionals] have to be very sensitive to someone with mental health issues. It needs to be asked sensitively and if a lady does say 'I do have a history of postnatal depression.' that is followed up'. (FG1)

'Women with mental health problems are usually aware of it and aware of their own needs ... [but] we [midwives] have to play it as presented... if she comes in and has been abusing alcohol or drugs or whatever we have to respond to whatever presents. Occasionally mothers do not want to disclose the abuse but you have to play it by ear'. (FG4)

The participants felt that the location of acute psychiatric facilities was a critical determinant in the referral of women with mental health issues. It was suggested that maternity units need to have a clear referral pathway. Specialist mental health services are available in a small number of maternity units. Participants from the mental health specialist services suggested that the number of women with mental health issues is on the increase, so a mechanism of referral and triaging to their services is needed.

'We [maternity unit] have a good referral mechanism if anybody has a history we refer to the mental health specialist and she sees them within 24 hrs'. (FG1)

'[If midwives were] aware of somebody with a previous condition [mental health] they will flag it, but they will generally go home routinely and if there is an acute psychotic episode, then it is out of our [midwives'] hands because the person will have to be referred to and seen by the Department of Psychiatry'. (FG2)

'Women tend to disclose ... low level disease ... at the clinic and then if problems arise during pregnancy, because we're [maternity unit] on the same site as the acute psychiatric facility, we [midwives] make referrals and they will come and see [the woman]'. (FG3)

'Provided the mother is recognising it [mental health illness] and compliant, the support from the psychiatric and/or psychology department is excellent, they will come at any time day or night'. (FG4)

'We [mental health specialist] see everyone from those with a planned pregnancy to those with unplanned pregnancy the variety is huge, like ... it's trying to be individual with the person, trying to give them choices and decisions, trying to include the GP, the public health nurses seeing what their [woman's] awareness and understanding of what is going to happening and giving them information and education'. (FG1)

A multidisciplinary team approach is essential.

'If you [mental health specialist midwife] had somebody, that has a mental health problem and they're very stable...they're on the medication, they've had a previous pregnancy and they're fine but you do have concerns about their medication we'll refer to [psychiatric team] to get a review'. (FG1)

'Inclusiveness and collaboration amongst professionals, inter-disciplinary teams notifying the maternity hospitals at an early stage [but] there has been occasions where people with quite a severe [mental health] diagnosis and no information was relayed to the maternity hospitals and suddenly it's the postnatal period and it's a very serious problem'. (FG1)

'We [maternity care assistant] would be always informed about how to deal with the mother and are always informed by the midwife and even though we don't have much information about mental health the midwives would tell us what needs to be done'. (FG1)

Screening for some mental health illnesses occurs.

'We're [midwives] most conscious of the postnatal depression or risk factors for it, that would be our biggest focus but we don't seem to have a high level of like schizophrenia or anything like that or even severe mental illness'. (FG3)

'We're [maternity unit] not actually asking about that [abuse], we are asking about psychiatric illness but at the moment we're not asking about history of sexual abuse or even domestic abuse'. (FG3)

Participants said that, once discharged, the maternity units generally have no contact with women. Usually the social worker will follow up women with mental health illness.

'Once the women get home from here [maternity unit] we [midwives] don't know anything about them, the social worker would, if she has been involved would certainly follow them up'. (FG3)

Locating and accessing community support structures can be the biggest challenge. Lack of social contact can be a problem if the woman is living in a rural area and this raises issues around professional responsibility and accountability for the public health nurse. There is no out-of-hours service available to women, which may *'enhance the woman's sense of isolation'* (FG5).

'GPs and the public health nurse are the 2 major sources [of support]. Link into the community that's where we [health professionals] fail'. (FG1)

Mother and baby unit/beds were also said to be difficult to access.

'That's a problem of a lack of beds in the mental health services for mothers and their babies ... it's a problem accessing beds that provide the services to meet the woman's needs'. (FG1)

'There's 2 beds down in [name of city] but they're not accessible because there's nobody to staff them and actually the adolescent service use them'. (FG3)

'A mother and baby unit is desperately needed, desperately needed in this county'. (FG4)

'More mother and baby units are needed'. (FG5)

7.3.4. Acceptability needs of women with disabilities during pregnancy, childbirth and early motherhood

7.3.4.1. Acceptability needs of women with a physical disability

In this theme of acceptability the relationship established between women with disabilities and the health service providers was discussed. There was a consensus that health professionals' experience of caring for women with a physical disability during pregnancy, childbirth and early motherhood is limited. When health professionals encounter such women they are learning new types of care and the challenges that arise depend on the degree of impairment experienced by the woman. Many obstacles can impede the assessment of a woman with a physical disability.

'There was limited experience of looking after women with paraplegia and pregnancy so we [midwives] did a search, to see was there any case reports on how they ... are managed. 'We [midwives] went on a big learning curve'. (FG3)

'We do have more women coming through with multiple sclerosis and ... they're an increasing kind of challenge depending on the degree of deficit that they have. But they're getting earlier diagnoses now so ... they're not as profound when they come in'. (FG3)

7.3.4.2. Acceptability needs of women with an intellectual disability or mental health difficulties

A lot of discussion was generated around the impact that loss of custody may have on the woman with an intellectual disability or mental health difficulties. The need to implement additional monitoring and support services for this cohort in order to ensure the health and safety of the child and the attainment of developmental milestones also generated a lot of discussion. The public health nurses and social workers identified how the needs of the mother and child are considered within the context of current legislation pertaining to the

protection and welfare of children. The best environment for the child must be determined and parents may need considerable support.

'The babies invariably have to go to fostering because they [woman with intellectual disability] wouldn't have the wherewithal to look after the baby without huge support and the family sometimes won't provide it for them, that support ... whether they wanted the baby or didn't want it or it was planned or not planned, they are just broken by it, really broken by it'. (FG3)

'For the parenting up to 2 years there would be more extensive monitoring and support services put in and possibly social work involvement to ensure the child is safe and being parented correctly and meeting their developmental milestones and an intellectual disability person ... under the Child Care Act you [health professionals] determine which is the best environment for the child and they [parents] possibly need 24 hour support for a moderate disability mum on her own who wants to continue to parent her child so it's the needs of the mum but still keeping within the legislation for the protection and welfare of the child'. (FG4)

7.3.5. Quality of services

Participants were asked to comment on the quality of services that are currently available for women from all 5 disability strands of the study. This question generated much discussion and the consensus is presented below.

'Could do better, like the election posters, we [one maternity unit] have started to use NALA, the adult literacy agency to proof read what we are publishing and asking them is this just plain and simple English so that anyone with English can understand it'. (FG1)

It was noted how the quality of care is guided by professional guidelines and current legislation. There was consensus that the quality of care is good but the quantity of support that women receive could be improved.

'We [midwives] ... we've got our philosophy of nursing we've got our guidelines, we've got the Equality Act, [name of specific HSE area] have their own equality policy we [maternity unit] tend to use those but that does not tell us what the quality of care is like ... the quality of care is as good as it can possibly be given the resources we have got'. (FG4)

The participants identified how in the majority of units, individualised planning of care and one-to-one sessions to facilitate the exchange of information is good. Different models of care such as DOMINO or Early Transfer Home services can be beneficial in helping women with disabilities to manage the transition to their parenting role and to perform parenting skills confidently in an environment adapted to their specific needs. Participants agreed that the provision of services is not uniform; good practice models exist but they are not standardised and often depend on staff having an interest in this specific area.

'The [quality of service is] patchy ... you have really good practice but they're not standard across the country they're not standard regionally not standard even within a hospital and it's often down to personalities who have an active interest in this area'. (FG1)

'People are well intentioned but it hasn't been a focus for services and the delivering of services'. (FG1)

Participants noted how service providers tend to adopt a generic approach to service provision, so for women with disabilities it can be difficult to provide appropriate services because they do not conform to the status quo. The availability of information in alternative and appropriate formats is minimal. Disability training and awareness programmes are provided but are sporadic.

'We try to normalise everything we keep trying to provide the broadest services for the most number of people and for the ones that have other needs it's very hard because you're trying to match the square peg to the round hole and it doesn't quite work'. (FG1)

'Not good for information [provision] we are not terribly well set up for information. We need to have awareness training for midwives, information in Braille or in audio or CD or something so we can give it out and ... mothers can keep it and look at it over and over again'. (FG4)

Health service managers spoke of the challenges they encountered when trying to attain and use resources to best effect.

'There is so many competing resources, [the maternity unit] is competing with pressure from the HSE or the DoHC [Department of Health and Children], to meet the targets for this year and you're [midwifery administration] watching where the resources are going and you are very focused ... everybody has come across a woman with some kind of disability that might be far greater than estimated and you try and get one thing that fits everybody, meets most needs and ticks the box'. (FG1)

Support services in the local community appeared better.

'In terms of family support services in the local community ... the support is excellent where we [social worker] have gone and looked for support for somebody who has gone home we have found that to be forthcoming'. (FG1)

The public health nurses commented on the needs of women with a hearing impairment in the community and the challenges involved.

'I'm sure the quality of care is excellent ... I would imagine they [women with hearing impairment] need far more public health nurse support visits than they are getting ... with regard to the quality of care and follow up visits they should be getting more than resource and caseloads allow'. (FG4)

'The voluntary agencies' links with the public health nurse is excellent, both as a resource and as a support. DeafHear is excellent, fantastic but the public health nurse could do more and would like to do more but the resources are not there'. (FG4)

For persons with an intellectual disability there are a lot of resources and supports available in the community in conjunction with intellectual disability services.

'In the community for persons with an intellectual disability who have had a baby there are a lot of resources and supports accessed in co [company] with community intellectual disability trained nurses who work alongside the public health nurse. They have a core of staff and resources that the public health nurse taps into'. (FG4)

The public health nurse provides very practical support for women with mental health difficulties. However, the psychiatric team do not always communicate

the woman's treatment programme to the public health nurse so in some cases the care can be fragmented and disjointed.

'Quite often it [care plan] is not communicated to the public health nurse what programme they [women with mental health difficulties] are offered or need'. (FG4)

One core issue that dominated the discussions was the lack of out-of-hours services for women with mental health difficulties. Participants noted how in the evenings and at weekends, responsibility with regard to the woman's safety reverts to family members.

'We [PHN] are operating a 9 to 5, Monday to Friday service; we haven't a plan to extend to out-of-hours services'. (FG2)

'Often in the community you have mothers who have attempted OD [overdose] or attempted suicide and the public health nurse is there she can only access NowDoc [GP out-of-hours service], casualty, or the GP or social worker and often they don't come or the hours have passed. Our [PHN] closest and best colleagues are often the Gardaí that get the child and mum out of there so it's a big worry and a big gap. Public health nurse services just work 9.30 to 5.30... not nights or weekends, so it's the out-of-hours where a lot of responsibility is put on the family unit'. (FG4)

7.3.6. Challenges to delivering services

Participants were asked to identify the greatest challenges in delivering services to women with disabilities. The following is an accumulation of the core challenges identified. There was a perception that there was insufficient legislation governing the provision of services for women with disabilities. Participants suggested that legislation is required to ensure the physical environment is accessible to all.

'We [maternity units] are all doing bits of building works in all our hospitals but if it [universal access for all] was somehow built into building requirements, it is in a lot of things ... but meeting the needs of all people is not there. Then we have a lost opportunity at architectural and contractual level and it's not just physical [disability] but all other disabilities as well'. (FG1)

'Legislation, you can have report after report but you need legislation ... you could address some issues but not all, like in relation to access and things like that but for the things we are trying to achieve [assessment of needs] there needs to be specific legislation for it'. (FG1)

Participants described the current services as fragmented. They identified the key challenges as; a lack of collaboration between professionals, *'attitudes of health professionals'* (FG5), a lack of disability awareness and training, insufficient information in appropriate formats, competing resources, increased workload or caseload and a lack of continuity of carer. Participants discussed the difficulties in accessing sign language interpreters and spoke about the need to develop professional guidelines and policies that could be implemented in all maternity units.

'Leaflets and information tends to be quite generic. The provision of adequate information would be a challenge'. (FG2)

'No Braille ... that's one of the biggest problems, there's no Braille and the other thing ... which may be good for antenatal teaching is to have a CD on antenatal teaching'. (FG4)

Participants identified specific challenges to women with mental health difficulties. These include no available data on the effects and consequences of mental health and a limited number of mother and baby units. The main challenge for the public health nurse is the lack of out-of-hours services, which is a source of anxiety and stress. The lack of collaboration or interdisciplinary approach to care between the community psychiatric nurse (CPN) and the public health nurse was also considered a major challenge.

'It's still a little alarming that there isn't an agreed minimum standard around the country. There's no kind of agreed strategy [mental health] or anything like that. We have no kind of national plan or regional plan'. (FG3)

'[With the] 2 strategies, a Vision of Change and a Transformation programme and primary care, there was no cross over at all. [They are there] in parallel pathways and nobody decided well listen I think that we better talk to this group over here'. (FG2)

'We don't know how it affects our women either in terms of how many of them suffer severe illness and what are the consequences in terms of even suicide. We don't gather that information. It's not reported ... that's very alarming'. (FG3)

Some health professionals lack education in the area of mental health care, have limited experience of engaging therapeutically with women who experience mental distress and lack awareness of the impact of mental health difficulties on women and mothers lives. The use of screening tools such as the Edinburgh Postnatal Depression Scale is not widespread and, despite the existence of agreed local referral pathways in some areas, the public health nurses have experienced challenges when attempting to implement referrals to specialist services. Often women are unaware of the services available and where to access these services.

'If the mother is non-compliant with her [treatment plan] or does not recognise her illness then we [midwives] have bigger challenges and our challenges would be staffing. You have to monitor mother and you have to be careful of baby care and the safety of the baby. You watch the mother who is apparently sliding into a psychosis of some kind and you think what is she capable of and it can be very frightening, very frightening. Very few midwives would have any psychiatric training'. (FG4)

'[The] Edinburgh Postnatal Depression Scale (EPDS) ... we[PHN] have tried to roll that out, in some areas in the country they have been successful ... but we are actually coming up against barriers, the actual psychiatric consultants themselves ... we have trained our public health nurses on the use of the Edinburgh Postnatal Scale, we have written up a policy on how to implement and all the rest of it but when the key player, the consultant psychiatrists, are not playing with us, it is very difficult'. (FG2)

'[The] referral pathway for us [PHN] in the community is to the GP and, with the greatest respect to the GPs, that depends entirely on the GP that you are referring to'. (FG2)

The challenges for women with an intellectual disability focused on the necessity to monitor parenting skills. The importance of sexual health education for these women was also discussed.

'The amount of sexual health education some of these young people receive [requires review] ... most of them are no longer in religious institutions, they're in voluntary institutions funded by the state but they have not made that transition to providing sexual health education for these young people'. (FG3)

'The challenges for mum with an intellectual disability can be so extreme from mild to severe there isn't enough resources there, isn't 24/7 from the public health nurse department. It's very much you [PHN] are going to walk out the door and you have the child welfare to think of and without the support of the family unit the challenges tend to be greater'. (FG4)

'The HSE, and HSE support and voluntary agencies all give a lot but all shut off at 5.30pm Monday to Friday and at the weekends there is [name of parenting supports], but social workers, nurses, all there Monday to Friday 9 to 5 but come nights at 8 or 9 or the weekend there is no one'. (FG4)

7.3.7. Addressing the challenges to service provision

Participants were asked to suggest measures to address the challenges encountered when providing care and services for women with disabilities. To enhance service provision for women with disabilities when accessing the publicly-funded health services during pregnancy, childbirth and early motherhood the following suggestions were made by the participants.

1. Develop professional guidelines, policies and integrated pathways to govern provision of care for women with a disability during pregnancy, childbirth and early motherhood.
2. Consider the development of community-based models of care to provide assistance and support when women with disabilities are discharged from the maternity units.

'There is a huge responsibility on the HSE corporate to acknowledge that this is a challenge [service provision] ... that we need to be supported in as frontline workers. The HSE corporate and the HSE have to look at this. This is an area that they have actually never sat down and looked at and started to ask questions about how can we

[health professionals] start delivering a service to this particular client group if it is something that has not been reviewed'. (FG2)

'Integrated care pathways would be the best way to address physical issues when she [woman with disability] accesses services'. (FG1)

3. Adopt a 'co-ordinated approach to the provision of services and care' (FG5) for women with disabilities.

'Looking at this [provision of services] in a very structured way. A lot of challenges can be overcome if there is links with particular services. Interdisciplinary communication within the hospital setting goes a long way to overcoming the challenges'. (FG2)

4. Address all structural barriers that render services physically inaccessible.

'Accessibility to our existing HSE buildings is not good'. (FG2)

5. Increase support in the community mental health services for mothers and their babies.

They [women with mental health issues] have so little services out there [community], what else can [midwives] do if they don't have somewhere that they can send this woman, if they don't have the therapy within the GP service, if they don't have counsellors, if there is one community nurse to cover half of [name of rural area]'. (FG3)

6. Consider developing and implementing a nurse-to-nurse referral pathway especially for mental health service users.

'It's a challenge for the public health nurse. It's such a worry and a stress, wondering if mum and baby are going to be alright until tomorrow ... another challenge from the public health nurse perspective would be the lack of communication and interdisciplinary work between the CPN [community psychiatric nurse] and public health nurse - it's good in some areas but not in others. The CPN may not know the public health nurse was in or vice versa or what treatment the woman is on, each discipline is working in their own kind of professionalism without linking with the other'. (FG4)

7. Establish more support groups in the community.

'[Health professionals] support them [women with disabilities] but they go out that door very quickly, so really their life is in the community and that is where the difficulties really are'. (FG2)

'[Women with disabilities should] be able to access a little bit of help. Nothing fancy, nothing very high tech, no masters, PhD people, just somebody to help them learn mothering skills, like a big sister project or something like that'. (FG3)

8. Maternity units should consider fostering links with disability services in the Local Health Office and voluntary organisations and agencies. A directory of voluntary organisations and agencies should be compiled and made available to all service users.

'Be very mindful that without the voluntary organisations and agencies out there we [public health nurses] would not be able to survive'. (FG2)

9. Provide disability training and awareness programmes for health professionals.

'Doing everything that we can to support them [women with disabilities] and to facilitate them and to make their journey as easy as possible... the disability teams that are established in all of the Local Health Offices it would be a good way of linking in with them to look at providing in-house training, not necessarily training at huge expense'. (FG2)

10. Consider inviting women with disabilities to become members of a forum or consider other mechanisms whereby women can provide feedback on services received.

7.4. Introduction to the focus group with intellectual disability service providers

In early September 2009, 6 services were invited by the National Federation of Voluntary Bodies to attend a focus group to discuss the challenges that pregnancy and early motherhood posed for intellectual disability (ID) services. Representatives of 4 services attended. These services were all from Leinster

and comprised both campus and community residential, day and vocational services. Two of the representatives were social workers, one was a senior nurse and the other a service administrator.

The specific aims of this focus group were:

- to explore ID service managements' perspectives on access to and responsiveness of public health services for women with intellectual disability who are pregnant, who have recently given birth or who are in the early stages of motherhood and to find out the service providers' experiences of pregnancy, child birth and early motherhood within their services;
- to identify the specific challenges that pregnancy and early motherhood pose for such services;
- to explore perceptions on continuity of care between ID services and health services in this regard;
- to elicit ideas from service providers for improvement of care to ensure that the needs of women with ID who are pregnant or in the early stages of motherhood, are addressed.

7.5. Findings - intellectual disability service providers

It was clear from the discussion that in the professional experience of the focus group participants the occurrence of pregnancy, childbirth and early motherhood is not common across the services. Whereas 3 individuals spoke of their experience of having to address this issue, one stated that no such incident had taken place in that service. It was agreed, though, that sexual relationships and pregnancy, in particular, posed complex challenges to all services at a number of levels: legal requirements; mother and child support; finances; and child protection.

It appears that services differ significantly in how they address sexuality for service users. It was acknowledged that, for 2 of the services, this was

shaped by the Criminal Law (Sexual Offences Act) 1993, which identified sexual intercourse with a person who has a 'mental impairment' as a basis for possible conviction. Thus, in those services, any sexual activity between service users was prohibited. This immediately placed an occurrence of pregnancy firmly within the context of breach of policy and, possibly, of criminal law. The other 2 services had developed policies that were focused on individual needs and preferences and the representatives confirmed that these could be constituted by some as potentially placing them in contravention of the above law.

It is clear though, that in one of the services that prohibited sexual activity, pregnancy had occurred and this was managed in a supportive, individualised manner. However supportive services can be, however, they appear to be caught in a difficult situation, balancing the rights and needs of the women in their care with legislation-based child protection issues. It was in this regard that the participants suggested that the foci of ID and public health services differed. This was most evident during the discussion of the HSE community childcare services that had been perceived in a negative light by the small number of women with ID who participated in this study. The service representatives similarly described their experiences of such services to be negative but noted that social services were often informed in their decisions by their experiences of managing child protection issues that arose in respect of women with ID who were not in receipt of specialist ID services, and who were not coping well. It was suggested that time and, in particular, financial resources were central to decisions to remove children from their mothers, and that this was a significant difference between them and the ID social workers. Social workers employed in ID settings are able to give time to women and children on their caseload, but this is not the situation for those working within general social services who are often under-resourced and who must, therefore, make decisions on the basis of 'child-first'. It was clearly noted though, that ID social workers' attempts to prevent crises by contacting HSE social services early in the pregnancy were often not responded to.

Thus, there was inadequate interagency communication and the involvement of social services occurred at a late stage when they realised the situation and considered the pregnancy to be a crisis pregnancy. The ID services, however, despite their ability to dedicate greater time to their caseload, are also limited in their ability to address the particular needs of mothers and children, as these are not accounted for within the finite financial resources that are made available for adult ID services.

Some services are attempting to address sexuality and its consequences through the provision of sex education, but much of this appears to be preventive in nature. Others have acquired living accommodation for couples but, despite the progressiveness of this, they acknowledge that they may not be in a position to support the inevitable need for accommodating family units. It was suggested that potential service user responses to prevention through prohibition was for sexual activity to 'go underground' or for service users to discharge themselves from service.

There was agreement that the general needs of the women with ID who had attended maternity services were well addressed, prior to involvement of the child protection team. It was identified, though, that care was not always individualised to the specific needs of these women and that the extra support was expected to have been provided by the ID services. Information, therefore, was not made accessible, and there was no commitment to give the women the time that they required to understand information, choices and decisions; this was left to the ID staff. Similarly, during the hospital stay, it was expected that ID services would provide personnel on a 24-hour basis to attend to the women's needs. It would appear from this, therefore, that continuity of care between ID and public services was lacking. This suggestion is reinforced by the fact that none of the focus group participants were aware of the fact that maternity services offer parent-craft classes to pregnant women, and by the reality that none of the women in their services

had availed of them. Parenting skills were, however, offered locally by at least one ID service.

In remediation of the above issues, the participants proposed that many of the problems were grounded in the training/preparation of professionals and in the need for clear guidelines regarding the care of women with ID.

Furthermore, it was suggested that there was a need to move towards more individualised services for women and mothers who have ID, and to move away from an overtly legalistic interpretation of this issue. In order for such individualisation to occur, it was suggested that there was a need for increased and individualised budgets to meet the needs of individual women.

7.6. Conclusion

When the focus groups were concluding participants were asked to identify one aspect that they would consider most important in the provision of services for women with disabilities. For women with a physical and sensory disability, the most important issue was access to, from and within the maternity unit/hospital.

'One-to-ones and recognising that people have difficulties, that's quite good ... [but] more in signage. We haven't really done anything about it because it's a resource issue. On the entrance to maternity [unit] there is a door bell, somebody speaks, they're [women with hearing impairment] not able to speak back, ... a second bell that will actually light up ... we haven't got that yet'. (FG3)

Participants highlighted the importance of developing and implementing an individual plan of care for all women regardless of their disability. An appropriate referral mechanism needs to be established and current services remodelled to facilitate better, efficient use of available resources.

'We [maternity services] have a lot of remodelling of current services [which] we could be doing better. We have and we could be using our resources much more effectively than we currently do. We have grown

up with a medicalised model of care and we have been slow to move despite an abundance of evidence and the pressure on our resources will actually be the catalyst to change that ... [we need] better use of resources not losing anything but gaining a lot'. (FG1)

Participants considered the community-based models of care as evidence of good practice when addressing the individual needs of women with disabilities. There was an overwhelming sense that current resources could be used more creatively and efficiently to meet the needs of women with disabilities but the out-of-hours services and a lack of community-based support structures and/or mother and baby units were considered a deficit that required immediate attention. Given that the women interviewed in the mental health strand identified the community support services as being of greatest help to them, that would appear to be the area that should receive most attention.

The education of professionals was identified as an urgent need and the need for clear guidelines regarding the care of women with disability, particularly intellectual disability, was noted. It was suggested that there was a need to move towards more individualised services for all women with disability, with concomitant increased and individualised budgets to meet the needs of women with intellectual disability living in supported accommodation.

Chapter 8 – Discussion

8.1. Introduction

The number of women of child-bearing age with a disability in Ireland is unknown, but figures from the Irish National Disability Survey show that approximately 20,000 women aged 18-34 and about 18,500 women aged 35-44 had a disability in one or more of the 9 categories used in the survey (Central Statistics Office, 2008). The most frequently-cited conditions for women of childbearing age were mental health conditions, pain, mobility, intellectual and learning disability, and difficulties in remembering and concentrating.

The aim of this study was to explore the strengths and weaknesses of publicly-funded Irish health services provided to women with a visual (V) or hearing impairment (H), a physical disability (P), a mental health difficulty (M) or an intellectual disability (ID) during pregnancy, childbirth and in the first 2 years of motherhood. Women were also asked about their experiences of accessing service providers and the service they received antenatally, perinatally and postnatally.

The findings report on the experiences of 78 women with disabilities from the Republic of Ireland and include women from all regional areas in the country and socio-economic groupings. In comparison with national statistics, the women taking part were the same average age (31.65 years compared with 31.1 years nationally), and the same parity (45% having their first baby compared with 42% nationally). Occupations were comparable, as the rates of home-makers (25% in the study sample and 24% nationally), semi-skilled (5% compared with 3%) and unemployed (4% compared with 3%), were similar. A higher proportion of the study sample were single, however (15% compared with a national rate of 32%) (ESRI, 2009). In general, the women with intellectual disability were younger, were unmarried and had a higher rate of

unemployment than women from the other strands, although the numbers are too small for any meaningful comparison.

In this chapter the findings will be discussed, and the strengths and weaknesses identified by the stakeholder groups will also be explored. The recommendations arising from the findings will also be reported. The data generated from the study identified issues related to the challenges faced by women with disabilities in their contact with maternity service providers in maternity units, and in the community and at home postnatally. Although the focus of this study was to explore the experiences of women with a disability accessing maternity care and early motherhood services specifically, some of the findings may of course apply to people without disability who are accessing health services in general. Reducing waiting times for maternity services, improving health information, and raising awareness among health professionals regarding women's concerns during pregnancy and childbirth will be of relevance to all women using these services. Indeed, some of the findings such as the need for easy to read information and the effectiveness of text messages for appointment times for those with hearing impairments could be applied broadly across the health services. The findings relate to 5 main themes: availability, which is the extent and type of service available to address the women's needs during pregnancy and in the 2 years following delivery; accessibility, which refers to how accessible the services are for women with disabilities; accommodation, referring to whether or not the services accommodate or change to meet the women's needs; acceptability and attitudes, which refer to the interpersonal relationships established between the women and health professionals; and affordability, which addresses the cost of services for women with disabilities .

8.2. Context of maternity care in Ireland

In 2008, the number of births in Ireland was 75,065 (Central Statistics Office, 2010), which is the highest number recorded since 1950. Maternity care is provided through 20 maternity hospitals/units, 19 of which are publicly funded, with a concentration of birth activity in the eastern region, and within the greater Dublin

area in particular. The current model of maternity care is, by international standards, predominantly hospital based as 99.9% of women give birth in one of the 20 units Ireland (Economic and Social Research Institute and the Department of Health and Children, 2009).

This has inevitably led to a consultant-led model of care that is highly medicalised (Devane et al, 2007; KPMG, 2008) and a diminution of the importance of women's experiences throughout childbirth. Many of these changes have resulted from an unprecedented move of birth from home to hospital in the 1950s, which has resulted in the centralisation of maternity services around the country with the majority of birth occurring in the 3 Dublin maternity hospitals. This project of centralisation has also resulted in women travelling long distances to the nearest unit.

The Maternal and Infant Scheme, which is the current framework within which maternity services are publicly-funded, refers to care provision by the GP in the community in consultation with the obstetrician in the hospital. The Scheme thus underpins the medical model to the exclusion of the acknowledgement of midwives as lead caregivers (KPMG 2008). This contract in its present format therefore militates against the development and provision of options for women such as midwifery-led care (hospital or community-based) (KPMG 2008). In addition, the role of private medical insurance has been instrumental in the maintenance of consultant led services (KPMG 2008, p8). This may influence the development and availability of choice within maternity care for women, as the contract addresses the lead professional exclusively as an obstetrician.

Although the majority of maternity units around the country are co-located with acute general hospitals and have access to the specialist services provided therein, Dublin is in a somewhat unique situation. The 3 free-standing maternity hospitals in the greater Dublin area vary in age and condition and are 'delivering their services in a suboptimal infrastructure' (KPMG, 2008:8). This situation impacts on all women accessing the maternity services.

This is further compounded by the fact that there is no current national framework for the future delivery of maternity care services. As the model of maternity care provision is funded within the acute services, there is a consequent lack of development of 'primary, community and continuing care services' (KPMG, 2008:8). Consequently, services are fragmented with little coordination between hospital, community, specialist services and the voluntary sector. There are no formal communication pathways between the maternity, mental health, voluntary and social welfare services for women who need to avail of these. Currently, the care pathway for women from confirmation of pregnancy up to 6 weeks postnatally is confined within the maternity services, with an absence of formal collaborative mechanisms with other services within the health and social sector. For example, there are no formal mechanisms to identify, assess individual needs and support women with disabilities from diagnosis of pregnancy up to and including the postnatal period. As there is no national framework to ensure access to advice and support from specialist services, there was variability in the service women with disabilities in this study received at an individual level. The context, as outlined, influences the delivery of maternity service to women in Ireland and has an impact on all women, not just women with disabilities.

8.3. Findings

8.3.1. The current models of maternity care

Successful provision and delivery of the best possible maternity services, including choice of care model, requires full engagement of service providers, commissioners and organisations. The findings of this study indicate a variation in the services available to women with disabilities, dependent on a number of factors including geographical location, co-location of the maternity unit with other specialist services, infrastructure of services and professional attitudes. Weaknesses identified included that, for some expectant women and mothers with mental health issues or intellectual disability, specialist services within the

maternity care sector were almost non-existent. Specialist mental health services were only available in two of the 19 maternity units (both based in Dublin) and no specialist services were identified for women with an intellectual disability. When services were available they were fragmented and un-coordinated, and choices to access a specific model of maternity care were constrained significantly by lack of resources and no strategic focus for care planning. The attitudes displayed to women in this study by some health professionals also impacted negatively on women's experiences of care.

There was a focus on medicalisation within maternity care services and the perceived impact of the woman's disability limited choices and, for some expectant women and mothers, this meant that their choice of birth was overridden by the professionals' decisions, thus reducing maternal autonomy. For example, when some women with a physical or sensory disability expressed a wish to give birth at home they met resistance from some professionals, a few going so far as to threaten to withdraw care if the woman proceeded with her plan. Women with a physical and sensory disability commented particularly on the lack of local availability of services, and inflexibility in appointment times leading to significant difficulties travelling to and from the maternity unit. Accessible public transport is not universally available, and this poses an additional difficulty. Some women reported having to travel by taxi as appointments were scheduled outside of the availability of public transport, with inherent cost implications being borne by the woman. Ideally access to midwifery-led care, which included home visits, would have ameliorated this difficulty.

Many women spoke of the lack of knowledge amongst maternity care staff regarding their particular disability and the need for an individual package of care to be developed in partnership early in their pregnancy. For women with a mental health issue, when access to specialised services was available, women reported on the positive impact on their wellbeing. Access to specialised services was contingent upon geographical location and good liaison between maternity care and mental health service providers. Women with limited or no access to publicly-

funded specialised psychological services had to resource these supports independently, which had significant financial implications for them. Women with an intellectual disability appeared to be more supported by social workers and others within specialist intellectual disability services. Case conferences were a routine component of antenatal care for these women, and these were helpful in ensuring continuity of care and access to appropriate services as required.

Similar concerns were expressed by women in the postnatal period where services were sourced and accessed opportunistically and on an *ad hoc* basis. For example, mothers with disabilities were advised by hospital staff that support would be provided on discharge from the unit/hospital through the public health nurse. Yet in reality, a poorly resourced community service was unable to deliver on this promise. For some women, inter-professional referrals did occur, but there was an absence of a clearly established link between the statutory and voluntary agencies, which have the potential to provide significant support and advice to women with a disability in pregnancy and motherhood. A similar lack of collaboration between agencies is prevalent in the literature and ‘falling between stools’ is frequently reported in disability studies.

The lack of services to women after birth also raised concerns for the new mothers who experienced an absence of publicly-funded community postnatal care services by midwives. In recent times, there has been an increase in community-based midwifery-led care provision in the form of DOMINO schemes, Early Transfer Home (ETH) schemes, community antenatal and postnatal clinics and 2 midwifery-led units. However, for women not accessing these specific services, there is no publicly-funded community midwifery service in Ireland. Currently, the State makes provision for one statutory visit to the mother and baby in the community by the Public Health Nurse (PHN). This single visit usually takes place in the first week following birth, and the number and timing of further visits, and/or referral to other services, are at the discretion of the PHN. Regulations related to the education and training of a

PHN no longer require a midwifery qualification. In addition, there is no requirement for a children's nursing or mental health qualification, which may have consequences on the care delivered in the medium to long term. Services for families who need support with early child care vary significantly across the country. Women in this study accessed such services by private funding, or by going to another country. This lack of community services provision for mothers and children is a key deficit within health care services in Ireland, where the community nursing services are currently under review. Often the focus of community support is on children in need rather than on families who require interventions and support and is provided by voluntary agencies, each of which has its own specific agenda and client group. Maternity services should implement and develop further inter-organisational communication to underpin service development if women with disabilities are to receive care that meets their individual needs.

8.3.2. Infrastructure

Although a centralised approach to the planning and delivery of maternity services is the dominant model in Ireland, the 3 Dublin maternity hospitals in particular have been identified as having 'ageing infrastructures that are not designed to deliver the range of maternity services required today' (HSE, 2005:11). Strengths identified in this study indicate that, in compliance with the Disability Act (2005), some positive changes to the physical infrastructure to accommodate women with disabilities to access the maternity units reasonably, have been undertaken. The Act also requires that maternity services adjust policies, practices and procedures to meet the needs of women with disabilities and this may include adaptation of equipment. It is appropriate and timely that maternity units address outstanding issues in relation to the physical build in any new developments, as weaknesses identified by this study included specific issues identified by women that continue to cause difficulty. For example, reception desks in clinics were frequently too high for wheelchair users to make contact with staff, and examination couches and baby cots were not always height adjustable. However, a strength identified was that

some staff attempted to address the woman's individual needs by sourcing the appropriate equipment to support independence with parent education skills.

As a consequence of a poorly resourced community care service, and the sometimes poor liaison between hospital and community staff, equipment and support personnel needed to maintain and foster independence were not always available once the mother and baby were discharged home. This was compounded further by the lack of liaison between the maternity and health and social welfare services at times. Some women therefore had to access support elsewhere, with a few having to depend on others or even pay for alternative care supports. Two women found the services so lacking that they left the jurisdiction to access care elsewhere. The issues of crossing borders to access health care in Ireland has also been reported by Stewart-Moore (2009).

8.3.3. Communication

A major weakness identified was that some women in this study experienced significant practical difficulties when communicating with health care staff at all stages of their experience of maternity services from confirmation of pregnancy to discharge and care at home. Verbal and written communication was the primary mode of interaction with staff and services for women with sensory disabilities, despite their impairment. For example, women with visual impairment had little access to written information in a usable format such as Braille. Women with hearing impairment experienced difficulties making contact with the healthcare provider to arrange appointments, as text and fax options, for example, were not always readily available. Contact with the emergency services was an issue of concern for women with a hearing impairment as they were not in a position to phone for an ambulance, and needed to depend on others for assistance. Although all women in this study had English as a first language, some women with a hearing impairment considered sign language to be their first language. The women who experienced mental health difficulties reported receiving little or no information on mental health problems, and were of the view that health care

practitioners were contributing to the silence around mental health problems during pregnancy and early motherhood. The findings indicate that ineffective communication was a significant concern for women and frequently had a negative impact on their experience of care.

The inflexibility of services and access to a range of models of care meant that consultant-led services were often unable to respond to women's particular communication needs throughout pregnancy and in early motherhood. Women highlighted the challenges encountered when attempting to make clinic appointments for themselves and their baby and attending antenatal education classes. These women indicated a need to have access to a text service to make appointments, extra consultation time with health professionals if lip reading without an interpreter, and access to individually focused antenatal education classes. These findings are similar to those of the National Disability Survey in Ireland, which found that, although 50% of people with a hearing disability had no difficulty communicating with health professionals, 10% reported that they were unable to communicate with them at all, and 37% had moderate difficulty communicating (Central Statistics Office, 2008).

Although some staff were very skilled in responding to women with a hearing impairment and used non-verbal gestures to be understood, others were less aware of the need for face-to-face positioning in front of the woman when speaking, and spoke while walking away or from behind theatre masks. Often a third party was involved in the communication process; for example, for those encounters that included the use of sign language interpreters. These may often have been family, friends or professional sign language interpreters, which caused the women some concern regarding confidentiality of their consultation. A minority of deaf women encountered great challenges when trying to get the health service providers to arrange a sign language interpreter; they met with resistance in doing so and often were advised that they would have to incur the cost of the interpreter. In addition, women expressed concern about the third party's expertise in communicating medical information accurately, and subsequent misinterpretation

of the information, which might impinge on the woman's ability to make informed choices. The Irish Translators' and Interpreters' Association (ITIA) have a code of ethics to guide the practice of professional translators while providing services (ITIA, 2009), which may offer some protection to women and ameliorate their concerns. Effective and innovative use of IT solutions needs to be considered in meeting the needs of these women.

Specific practical difficulties for women with a visual impairment emerged. These included confirmation of pregnancy (reading the pregnancy test strip), seeing the fetal ultrasound and making up formula feeds. Although these seem like irresolvable situations they need to be considered by carers when planning supportive care for expectant women, mothers and children. Similar findings regarding access to the environment and practical resources within maternity and related services have been reported by Thomas and Curtis (1997). McFarlene (2004) reports the difficulties women with a visual impairment experience within the health care setting. Women in this study required written information to be translated into Braille, or to have access to an audio resource, which was not available in any of the services.

The majority of women with a sensory impairment described how the interaction, communication and interpersonal skills of health professionals were impeded by a lack of awareness and sensitivity around their impairment. As a consequence women felt ignored and detached from the situation, which had a negative impact on their experience of becoming a mother. The HSE (2005) review of maternity care services in the Eastern Region suggests that women should increasingly exercise their right to be involved in 'decision making' about how and where they would like to give birth (p13). A weakness identified in this study was that, for some women, this standard was not achieved.

Similar issues arose for women with an intellectual disability who expressed their dissatisfaction when health professionals did not communicate with them directly, but rather with an advocate or family member. A strength noted was that some

staff, particularly midwives, were perceived to have been more woman-centred in their approach.

8.3.4. Women-centred care

The findings from this study indicate the need to focus on women with a disability at an individual level within the services provided. During pregnancy and the early newborn period, women are in contact with a range of services, both statutory and voluntary within the acute and community sector. Each of these services has a responsibility for the quality of care delivered to expectant women, mothers and babies and adherence to the legislation related to disability and equality.

Within this study, many women described experiences reflective of a focus on service provision rather than on a women-centred approach to care, which highlighted a weakness in the services. Women expressed concerns regarding the appropriateness of their care and issues related to informed consent. Some women recalled encounters with caregivers that were insensitive, inappropriate, stigmatising and discriminatory (as well as others that demonstrated empathy and sensitivity to their needs). This is potentially due to a lack of familiarity with the woman's specific needs related to her disability or impairment.

In relation to those with mental health difficulties, women reported that there was a lack of understanding around their distress. Consequently, these women described encounters with healthcare professionals that were insensitive, unsupportive and lacked empathy. Midwives, in particular, needed to create a supportive space for women to talk about their distress. In addition, women reported communication failures in providing verbal or written information on mental health issues and pregnancy. As continuity of care was not routine, women found that they had to repeat their history to a range of health professionals over the course of time. A potential solution may be to have a central electronic data record information system that can be accessed by all relevant health professionals involved in providing care. Major strengths reported were the existence of specialist mental

health services for women in 2 maternity hospitals, the community mental health support group in one other area, individual therapy and a strong support system by community mental health nurses.

Many complex issues surround disability, and those with a disability face many barriers including 'separation and segregation, stereotyping, labelling and stigma' (RCN, 2007:4). Although some women reported strengths in terms of positive interactions with midwives and other health professionals that were characterised by being treated in a respectful and dignified manner, others reported less positive experiences. These negative interactions with staff may be reflective of a stereotypically negative view of disability. Thomas and Curtis (1997) also found similar instances of disempowering practices that can result in "serious undermining of disabled women's confidence and belief in their abilities to be 'good' mothers" (p209). Promoting equality for women with disabilities will involve significant efforts to overcome these barriers. The women in this study wished to be treated in the same way as any other woman becoming a mother and for them, maintaining a sense of normality rather than disability was important. Women also reported that some professionals focused on the impact of the woman's disability on the child, and relative risks associated with inheritance, which was described by women as unhelpful and inappropriate. Women with physical disability, sensory impairment, a mental health issue or an intellectual disability felt their capacity to become a mother and care for their child was frequently questioned by health professionals. For example, some women with a physical disability reported that health professionals were more intent on dissuading them and their partner to forego pregnancy rather than to support them in becoming parents. Women with a sensory impairment also felt disempowered when professionals communicated inappropriately, for example by referring to them in the third person. These stigmatising practices need to be addressed by providing education programmes for relevant staff.

A weakness identified by this study was the sense of stigma expressed, particularly by women with mental health issues as they spoke of the lack of understanding

that health professionals had of their distress. This left women feeling vulnerable and many described feeling that they were constantly under surveillance. This on occasion led to women feeling isolated and frustrated. The feeling of being observed and watched as they cared for their child was not reported by all women but the fear of losing custody of their baby was very real for women with mental health issues or intellectual disability. The surveillance described by some of these women may be influenced by the focus on child protection legislation in Ireland, which places a significant responsibility on all health professionals to identify children at risk (Department of Health and Children, 2004). Mothers with disabilities also felt that they were expected to achieve parenting skills as demonstrated by other mothers, without receiving sufficient support. In the UK, the “Framework for the Assessment of Children in Need and their Families” (Cleaver and Nicholson, 2003) is used as an objective way of measuring parental abilities. On occasion, as part of their child protection role, it is necessary for health professionals to assess people’s ability to parent, but such assessment should be performed professionally, transparently, and fairly with due cognisance of the vulnerabilities and challenges faced by parents with disabilities. Booth and Booth (2005) recommend that a common assessment tool be used, with clear, explicit criteria and that the parents be engaged actively in the process, which should take place in their own home, with support.

Women-centredness reflects the principle of people-centredness in the National Health Strategy (Department of Health and Children, 2001). The interdisciplinary team providing maternity care to women comprises a wide range of professionals in order to deliver quality care for women. Birth rates in Ireland are increasing and, when combined with a current moratorium on recruitment of staff to the public sector, the challenges to plan and deliver effective care cannot be underestimated. Women rightly expect to be offered choices in the model of maternity care offered, to have access to continuity of carer, and to have access to information in order to participate in effective decision making when care is being planned and delivered. Within each unit a focus on human resources and workforce planning, and training

needs analysis, is of paramount importance if the service is to become more responsive to the expectations of women with disabilities.

Quality improvement mechanisms ‘must be inherent in the development of maternity services’ (HSE, 2005:17). It is therefore essential that the structure, process and outcomes of services be developed and evaluated for all women including those with a disability. The HSE (2005) review of maternity services in the Eastern Region makes significant recommendations regarding the strategic and local planning and delivery of maternity services, and indicators of good practice are suggested. Similar recommendations to improve and modernise service configuration and models of care are made in the KPMG (2008) report on publicly funded maternity services in the Greater Dublin Area (GDA). Adoption of the model recommended within the report “will promote greater integration of both acute and community, paediatric and maternity services across the GDA” (KPMG, 2008: 223). This report makes further recommendations to include a review of current clinical governance arrangements, service re-design and the development of clinical care pathways as part of quality improvement. A framework for collaborative practice that is both women-centred and evidence-based for women accessing maternity services, including those with a disability, should be implemented.

8.3.5. The need for flexible maternity care

It is crucially important that maternity services are also sufficiently flexible to meet women’s needs whilst ensuring the safety of both mother and baby during pregnancy, childbirth and early motherhood. In Ireland, the National Health Strategy (Department of Health and Children, 2001) proposes that the future development of maternity services should be based on the principles of access, equity, accountability, safety and women-centredness (p2). The findings indicate a weakness in that these principles were not achieved for all women who took part in this study, and there is therefore a need to develop and improve Irish maternity services. Future initiatives should involve offering more options in relation to the model of care available to women than are currently provided. For example, the implementation of community based

models of care such as DOMINO schemes (KPMG, 2008) and midwifery-led units, as recommended by two recent reports (KPMG, 2008; Begley et al, 2009c), would facilitate the delivery of more women-centred maternity services, including offering care in the home. For such changes to occur, the Maternal and Infant Care Scheme and private health insurance stipulations that underpin current maternity care service provision should be revised to include the midwife as a lead clinician in the provision of care.

8.3.6. The need for integrated, collaborative services

Weaknesses identified by the women in this study indicated that a fragmented approach to care is common across the country. Women's experiences reflect the absence of a planned, individualised approach to care resulting in difficulties accessing services, receiving appropriate and timely information from professionals and a lack of support in the community following the birth of their baby. In order to address this situation, an effective model of interdisciplinary referral across a range of providers within maternity, specialist and community services is required. The HSE (2005) review offers recommendations on the use of information technology that should be prioritised to improve communication between maternity care staff, specialist services, GPs and others. Evidence from the study suggests that when a breakdown in communication occurred amongst health professionals, there was an obvious impact on women's experiences of care. Some women recalled being offered considerable support in the community by the public health nurse, which was identified as a strength of the services; however, on many occasions these promises remained unfulfilled leaving some women feeling powerless and unsupported. Consequently, referral pathways not only need to be evidence-based but require sufficient resources if services are to be delivered in an effective, reliable and timely manner.

There is also a need to establish functional relationships and close working partnerships between statutory and voluntary agencies to ensure women have easy access to services. Within this study, women did access voluntary agencies

for support whether from their own action or by referral from a health professional, but this was on an *ad hoc* basis. It is suggested that best practice models for service provision for women with a disability could be based on international frameworks developed for other groups such as for children with a disability. Such models include the allocation of a key worker and the development of recognised care pathways specific to the individual from the point of identification of need.

8.3.7. The need for education of health professionals

In order to meet the specific needs and expectations of women with a disability, secure funding must be allocated for adequate education of staff. Supports must be made available to ensure staff can address competently and professionally the issues related to working with women with a disability. This will enable the implementation of best practice guidelines designed to meet individual needs, keeping the focus of care that is women-centred rather than service-driven. Deficits in communication between service providers and women with a disability identified as a weakness in this study suggest that there is a need for resources for service providers to have access to appropriate education relating to issues of disability awareness, rights and equality. Examples of insensitive encounters include situations where women in labour were not provided with appropriate information in order to give consent for care. In addition, women with a visual impairment, when written consent was required, were often bypassed and consent was sought from and provided by a proxy. For women with an intellectual disability, informed consent to interventions was not sought directly and consistently by midwives when providing care during labour and during early motherhood, but was sought from a third party. Staff awareness of the legal and professional issues around consent that arise in caring for women with disability thus needs to be developed.

8.4. Summary

The findings from this study demonstrate that women's experiences of the publicly-funded maternity services are varied, with weaknesses and strengths identified. Some situations did occur in which the service received was suboptimal and did

not meet women's expectations and needs. These findings are supported by the data from the focus group interviews with health professionals, who indicated their awareness of deficits in service provision, which caused them concern. Health professionals proposed measures to address the deficits and to enhance service provision, which should be considered actively when planning services for women with a disability in the future. Midwives within the focus groups highlighted a deficit in their knowledge and expertise in caring for women with mental health issues, which may be resolved by further education. Having identified issues common to women with disability, focus group participants also reported issues that related directly to the specific disability experienced. Women with a physical disability raised issues relating to the environment and the impact of the disability on their ability to remain independent while pregnant. Women with mental health issues reported difficulties in accessing services, a reluctance of staff to discuss any issues relating to mental health including antenatal or postnatal depression, anxiety, or psychosis and stated that they received inconsistent advice regarding medications in pregnancy and in the newborn period.

Women with sensory impairments identified difficulties in terms of the availability of written information in an appropriate format, and in the use of interpreters, with consequent reliance on others for the exchange of information. Women with an intellectual disability seemed to receive more support through the involvement of social and support workers, although HSE community childcare service personnel's perceived concerns regarding child safety and custody were raised by these women and their support workers. Despite the infrastructural and interpersonal communication issues reported, many women identified positive encounters with individual staff members in the hospital and community, demonstrating strengths in the services.

Service providers acknowledged service deficits, and the need for change and expressed a willingness to change. Similar knowledge deficiencies and the willingness for staff to be involved in change were also identified in the KPMG (2008) report.

The process of developing a women-centred service for women with disability within maternity care is complex. Changes in service delivery will necessitate extensive consultation across the professions, and interprofessional education may be a way forward. The development of any educational programme must be based on a collaborative model of interprofessional working, to include active involvement of service users/families and the voluntary sector if services are to support the true integration of women with a disability.

Factors influencing the experiences of women with disabilities include strategic, local and interpersonal issues related to the predominant configuration of the maternity services within the acute sector to the detriment of the development of support within primary care. The issues raised by women in this study are not unique to women in Ireland and support similar findings in international studies. Discriminatory practices may be based on “our society’s normative assumption that disabled women are fundamentally *dependent*” (Thomas and Curtis 1997: 208) and that without the support of non-disabled people they are rendered relatively helpless. The help that is offered is often inappropriate, and access to timely, effective, reliable assistance is problematic. Within Ireland the legislation aimed to protect people with disability, and the principles, need to be fully enacted in clinical practice. Discriminatory practices, as identified within this study, had a significant effect on the physical, psychological and social wellbeing of the women as they became mothers. Legislation prohibits discrimination on the grounds of disability, and women with disability should be supported to become a mother in the same way as other women. For many women in this study, retaining a sense of normality was a key objective. Future service developments must therefore be underpinned by a philosophy of normality and include stakeholder involvement.

8.5. Recommendations

From these findings the following recommendations are made:

8.5.1. For the Department of Justice, Equality and Law Reform

It is recommended that:

- Section 5 of the Criminal Law (Sexual Offences) Act 1993 be amended, as a matter of urgency, to enable the decriminalising of sexual relationships between adults who have capacity to consent.

8.5.2. For the Department of Health and Children

It is recommended that:

- A national review of maternity services in Ireland be undertaken urgently, focussing specifically on the development of an integrated care pathway to ensure that women with disabilities have full and equitable access to services that meet their individualised needs, in line with current equality, anti-discrimination and disability legislation
- A coherent inter-agency approach to service planning and delivery within and between maternity, disability and other relevant services is developed based on international best practice
- A collaborative care electronic record system, which should include the capture of specific data relating to women with disabilities, should be introduced to ensure continuity of care across HSE boundaries
- A review of the current funding arrangements within the Maternal and Infant Care Scheme should be conducted to facilitate the funding of a greater choice of maternity care models for all women in Ireland

8.5.3. For the Health Service Executive (and partner agencies)

It is recommended that:

- Specific national data regarding women with disability during pregnancy and early motherhood are collected as part of ongoing perinatal and disability databases
- Services for women with disability are incorporated fully into all service development plans, clinical protocols and practice guidelines within primary, secondary and tertiary care with immediate effect
- A coherent and comprehensive national infrastructure to support all new mothers with disabilities and their family is planned, implemented and evaluated, to include the introduction of a national midwifery disability advisor
- Current community midwifery services should be developed further to meet the specific needs of women with disabilities, and subsequently evaluated for effectiveness
- Within the intellectual disability sector the specific service requirements of women with intellectual disability who become pregnant are addressed
- Community mental health services be developed further to ensure that women who experience mental health problems during pregnancy or early motherhood are adequately supported in the community
- Current expenditure within the maternity, mental health and intellectual disability care sectors should be reviewed in terms of its effectiveness in meeting the needs of women with disabilities, and these needs should be given priority in funding allocation
- Liaison and collaboration with the voluntary and social welfare sector should be developed to support an integrated care pathway designed to meet women's individual needs

- Interprofessional communication structures within and across service providers be developed to ensure continuity of individualised care
- Formalised structures should be created to facilitate service user involvement at all levels of service planning.

8.5.4. For maternity hospitals/units (including community care)

It is recommended that:

- Interprofessional guidelines and protocols related to the provision of maternity services to women with a disability should be developed, in conjunction with service user representatives, to provide guidance on supports required by women with disabilities, accessible premises, how to communicate etc.
- Disability awareness education should be provided for all relevant staff
- Structural adaptations be undertaken to improve the accessibility of maternity services, including the provision of more single accessible rooms to meet the diverse range of health needs of women with disabilities
- Equipment needed to provide individualised care for women with disabilities be resourced by maternity care providers immediately
- Current *ad hoc* liaison mechanisms between the maternity services and other specialist and social services and voluntary agencies be formalised to support an integrated care pathway designed to meet women's individual needs
- Needs of women with disabilities are assessed at the first point of contact and individualised care pathways are planned, implemented and evaluated throughout in conjunction with each woman

- The provision and use of third parties, including translators should be reviewed and resourced appropriately to reduce the issue of fragmented care
- Appropriate communication and information resources are developed in a range of accessible formats such as Braille, or audio resources
- Models of care that facilitate continuity of carer and increased care in the community, such as midwifery-led care or DOMINO schemes, should be implemented nationally
- Current maternity records be adapted with immediate effect in order to identify clear information on specific needs for women with a disability and the interventions required to meet these needs
- Cost neutral changes to ensure quality care within current maternity services are implemented as soon as possible to include:
 - Flexibility in appointments/location
 - Information for all women on mental health issues
 - Adequate consultation times allocated for individual assessment of needs to be undertaken.

8.5.5. For professional bodies

It is recommended that:

- Specific post-registration educational programmes for all staff working with women with disability be developed in conjunction with service providers, training providers and service users
- Equality and diversity training (human rights) and disability issues be included in all curricular guidelines and standards in professional undergraduate and postgraduate programmes in midwifery, nursing, medical and allied health professional education
- The needs of women who experience mental health problems during pregnancy and early motherhood be included in all curricular

guidelines and standards in professional undergraduate and postgraduate programmes in midwifery, nursing, medical and allied health professional education

- Interprofessional evidence-based guidelines for the care of women with a disability be developed and implemented as a matter of urgency
- The National Council for the Professional Development of Nursing and Midwifery support the creation and development of innovative specialist posts at Clinical Midwife Specialist or Advanced Midwife Practitioner level to support women with disability.

8.5.6. For voluntary agencies and support groups

It is recommended that:

- Peer support groups become more involved in seeking services required at a local and national level
- Networks between current support services/groups are established to strengthen the service users' input
- Support groups seek training and funding to enhance their members' participation as advocates for service users and involvement in professional education programmes and service planning. As was suggested during the course of this research, agencies should explore the potential of establishing a 'big sister' type mentoring programme to support women with disabilities through the antenatal and early motherhood period
- Agencies create, fund and evaluate the development of centralised information resources funded by voluntary and statutory services. Examples of current good practices include
 - A parent-to-parent 24 hour helpline
 - HSE website 'Your service, Your Say'.

- Voluntary and statutory providers of intellectual disability services undertake an audit to estimate the prevalence of pregnancy amongst women with intellectual disabilities and to identify the issues that pregnancy presents for such services.

8.5.7. For women with disabilities

It is recommended that:

- Women with disabilities seek active involvement in achieving representation through groups such as the Irish Patients' Association, The Irish Advocacy Network, National Service Users' Executive, and Inclusion Ireland
- Women with disabilities make known their preferences for care within maternity services to inform service provision and future development
- Women with disabilities as service users become involved actively in the development, delivery and evaluation of all support services across the health care sectors
- Women with disabilities consider liaising with local voluntary agencies to seek a platform to ensure that their voices are heard.

8.5.8. Further research

It is recommended that further research be undertaken within Ireland to:

- Explore health inequalities further within maternity services, and their consequences for the wellbeing and quality of life of women with a disability, and for the child and family
- Investigate effective mechanisms of reducing discriminatory attitudes towards women with disabilities, and supporting service

user involvement in service planning and delivery, to improve equity within the service

- Explore the experiences of partners, significant others and other family members in supporting women with disabilities through the maternity period.

8.6. Conclusion

In conducting this national study, significant understanding has been reached of the needs of women with a disability accessing maternity and early motherhood services. The findings suggest that although service providers are endeavouring to implement the requirements of current legislation and to offer quality care, some further challenges remain. These are frequently related to structural and infrastructural issues within hospital and community care areas, which should be addressed. The recommendations from this study should be considered as a baseline to take forward future developments to improve maternity service planning and delivery for women with disabilities. Greater choice of maternity care models and the meaningful inclusion of service user/provider input is required at local and national levels if an internationally renowned maternity service is to be developed to meet the needs of women with a disability in the 21st century.

The aim of this study was to explore the strengths and weaknesses of the publicly-funded Irish health services provided for women in 5 disability groups. The findings provide a context to inform the key issues that need to be addressed to care for women with disabilities in Ireland. The local gaps in service found indicate that there is a need to develop further a more appropriate, accessible and equitable maternity service throughout the country, to ensure that the concerns of women with disability who are in receipt of such services are addressed.

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Appendices

Appendix 1 List of voluntary agencies contacted

1	Disability Federation Ireland
2	People with Disabilities in Ireland
3	Irish Deaf Society
4	DeafHear
5	Kerry Network of People with Disabilities
6	Brainwave
7	Irish Wheelchair Association
8	Spinal Injuries Ireland
9	Rehab Ireland
10	MS Ireland
11	National Council for the Blind of Ireland
12	Irish Guide Dogs for the Blind
13	Irish Advocacy Network
14	Schizophrenia Ireland now called SHINE- Supporting People Affected by Mental Ill-Health
15	Inclusion Ireland
16	GROW
17	Frontline
18	Aware
19	Mental Health Ireland
20	OANDA
21	Headway Ireland
22	Bodywhys
23	Recovery Inc.
24	Western Alliance for Mental Health
25	Federation of Voluntary Bodies of Ireland
26	Camphill Communities
27	St John of God's
28	St Michael's House
29	Step Enterprise
30	Sunbeam House
31	Cheshire Ireland
32	St. Stewart's Hospital
33	Malta Services Drogheda
34	Sisters of Charity, Jesus and Mary, Moore Abbey
35	Brothers of Charity
36	The National Institute for Intellectual Disability TCD
37	COPE Foundation
38	Irish Deaf Women's Group
39	Women With Disabilities in the West
40	Womens Together Network
41	PND Support Group
42	Polio Support Group
43	Aims Ireland
44	MagicMum
45	Rollercoaster

Appendix 2 The study methodology

1. Introduction

This study, part of a 3-part project, was commissioned by the National Disability Authority (NDA), in a joint initiative with the National Women's Council of Ireland (NWCi), to explore the strengths and weaknesses of publicly-funded health services in Ireland provided for women with disabilities in relation to pregnancy, childbirth and early motherhood. The report presents the findings of a nation-wide study and complements the 2 companion documents forming the first 2 sections of the study, also commissioned by the NDA. The first of these was a comprehensive 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, 2009a). The second (Begley et al, 2009b), presents a review of Irish and international social policies relating to disability and childbirth. Together, these 2 documents outline the legal and practical provision of publicly-funded health services for women with disabilities in Ireland and 9 other countries, and provide the background for this detailed exploration of women's views and experiences of the services they received.

Various authors (Wagner, 2001; Devane et al, 2007; KPMG, 2008) have noted that childbirth in Ireland has become more medicalised, particularly over the past 2 decades and women with disabilities may therefore be at risk of being viewed as having a medical problem solely because of their particular disability. Internationally, the literature relating to the care of women with all types of disabilities shows a history of discrimination. Evidence from the literature sourced for Part 1 of the study (Begley et al, 2009a) suggests that society has undervalued women with disabilities, has exerted control over their sexual and reproductive lives and, in many cases, has exacerbated their

difficulties. Mothers with intellectual disabilities or mental health difficulties, in particular, are often considered an antithesis to the stereotypical 'ideal' mother, separated from their children, whether or not there is evidence of risk of harm (Begley et al, 2009a). A 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 services and care (Begley et al, 2009b).

The National Disability Authority (NDA) and National Women's Council of Ireland (NWCI) have previously highlighted the need to improve access to reproductive and sexual health services for women with disabilities in Ireland, as well as the need for disability awareness training among health professionals (NWCI, 2001; NDA, 2007). Evidence from the NDA's second national attitudes survey suggests that people's attitudes towards disability are improving (NDA, 2007) but it is apparent that some negative attitudes persist. At the start of this project, no study had prospectively set out to undertake any detailed exploration of the views and experiences of women with disabilities in Ireland in relation to maternity care.

The starting point for any change in service provision has to be with the individuals seeking that service (Kennedy and Murphy-Lawless, 2002), so if access to health services during childbirth, pregnancy and early motherhood was to be improved for women with disabilities, their experiences had to be documented. This study aimed to address this gap in research by seeking the experiences of women with disabilities in terms of the strengths and weaknesses of publicly-funded Irish health services provided to them in relation to pregnancy, childbirth, and early motherhood, with a view to informing the development and improvement of maternity care services for women with disability in Ireland.

2. Aim and objectives

2.1. Aim

To explore the strengths and weaknesses of publicly-funded Irish health services provided to the following groups of women:

- (a) Women with a visual impairment (V)
- (b) Women with a hearing impairment (H)
- (c) Women with a physical disability (P)
- (d) Women with a mental health difficulty (M)
- (e) Women with an intellectual disability (ID)

2.2. Objectives

- a) To ascertain and explore the views and experiences of women with disabilities, throughout the country and across all socio-economic groupings, in relation to
 - the strengths and weaknesses they encountered in publicly-funded Irish health services during pregnancy, childbirth and in the first 2 years of motherhood,
 - their experiences of accessing general practitioners, practice nurses, midwives, obstetricians, neonatologists, paediatricians, allied health professionals, public health nurses and public health doctors, health care workers, family support workers, and
 - the service they received;
- b) To seek and discuss the views of the relevant service providers as to strengths and weaknesses of the services provided and their opinion on the development required;
- c) To make clear recommendations as to how the experience of engaging with the various publicly-funded Irish health service providers during pregnancy, childbirth and early motherhood can be improved for women with disabilities, and to do this in such a way as to maximise the likelihood of the report influencing policy-making.

3. Definition of terms

The way in which 'disability' is defined and understood can have implications for how people with disabilities are perceived and treated. Factors such as gender, class, sexuality and age, structure the experience of people with disabilities. There are many definitions of 'disability' but the team has chosen the definition of the International Classification of Functioning Disability and Health (ICF) to guide the study. This definition states: 'Disability is a decrement in functioning at the body, individual or societal level that arises when an individual with a health condition encounters barriers in the environment' (World Health Organisation, 2001). Within an Irish context the Disability Act (Government of Ireland, 2005: 6), which is informed by the ICF framework, defines disability as 'a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment.'

4. Study methods

4.1. Design

A qualitative descriptive design was used to ascertain and explore the views and experiences of women with disabilities throughout Ireland. Rich, in-depth data were gathered from 78 women with a disability who had experience of, or were currently receiving care from, the maternity and early motherhood services. In order to ensure that women with multiple experiences and outcomes were sampled, women from many backgrounds and geographical locations were invited to participate. The views of relevant service providers were also sought through focus groups.

4.2. Study population

Preliminary attempts to identify the 5 populations of women (women with visual impairment (V), hearing impairment (H), physical disability (P), mental health difficulty (M) or intellectual disability (ID)) revealed that few comprehensive databases exist in this regard. Thus, the populations could not be readily delineated. Furthermore, contacts with individuals and bodies representing people with mental health difficulties and intellectual disabilities suggested that these women might be very difficult to access and, in relation to women with ID, could be few in number. It was proposed to interview 90 women, 30 during pregnancy, 30 during the immediate post-natal period (up to 6 months), and 30 during early motherhood (6 months to 2 years). Each of these groups was to comprise of approximately 6 women with visual impairment, hearing impairment, physical disability, mental health difficulty or intellectual disability, respectively. The National Disability Survey figures (Central Statistics Office, 2008: Table 1.10) show that 9.3% of people in Ireland have a disability, and that 23% of women with a disability are aged 18-44, so approximately 2.2% of women of childbearing age would have a disability. As there were 75,065 births in 2008, the inclusion of 90 women in this study would represent approximately 5.5% of a possible total of 1651 women with disabilities aged 18-44 years who gave birth in 2008.

4.3. Characteristics of the study population

In general, the women self-reported their disability when presenting for participation in the study and no stringent checks were made to verify their account. However, it was usually obvious that women had the impairment that they described. The defining characteristics identified as guiding the entry criteria for each population group were:

(a) Women with **a visual impairment**, according to the Irish legal definition relating to the award of the Blind Pension guidelines of "best corrected vision must be equal to or less than 6/60 in the better eye or field of vision must be

limited to the extent that the widest diameter of vision subtends an angle not greater than 20 degrees" (Government of Ireland, 2009).

(b) Women with **a hearing impairment**, whose hearing is reported by them to be affected to an extent that renders the understanding of speech through the ear alone, with or without a hearing aid, difficult or impossible.

(c) Women with **a physical disability**, defined as a decrement in functioning due to a physical health condition e.g. multiple sclerosis, paralysis or loss of one or more limbs, epilepsy.

(d) Women who have faced **mental health challenges** that required contact with the mental health services prior to, during or after pregnancy. Contact with the mental health services included use of outpatient psychiatric care facilities; admission to inpatient psychiatric hospitals; use of day hospitals, day care centres; living in community residences; contact with a psychiatrist, psychiatric nurse, psychologist or social worker employed by the mental health services; out-patient domiciliary visits; and general hospital psychiatric liaison services. It was desired that a number of women who had experienced psychotic episodes and a range of other enduring mental health problems such as schizophrenia and major affective disorders would volunteer for inclusion, in addition to women who experienced anxiety or depression. However, given the known negative consequences of applying specific diagnostic labels to people, the debates around the variability in diagnosis of enduring mental illness, and the possibility that a woman may not be aware of her diagnosis or that her diagnosis may have changed over time, diagnosis did not form part of the selection criteria. Consequently, it was important that women self-identified as having a mental health problem.

(e) Women who have **a mild or moderate intellectual disability** who are, or have been, in receipt of, or who are identified as needing, specialist health, social and education services.

All participants in this study volunteered to take part and self-identified themselves as having a disability in one or more of the above categories. In the case of women self-identifying as having a visual impairment, all were in receipt of the Blind Person's pension. All women in the hearing impairment strand contacted the research team through DeafHear. All those with physical disabilities were obviously disabled by their particular condition. Women volunteering in the mental health strand had a variety of mental health difficulties (section 1.2.5.) and those presenting with intellectual disability were all in receipt of services for those with an intellectual disability.

4.4. Inclusion and exclusion criteria - individual interviews

Inclusion criteria: Women with a disability, as above, and were a) currently pregnant, and/or b) had given birth in the past 6 months and/or c) had given birth in the period 6 months to 2 years ago.

Exclusion criteria: Women who were considered to be unable to give informed consent on the day of the interview..

4.5. Inclusion and exclusion criteria - focus groups with health professionals

The inclusion criterion for participants in the focus groups was solely that they have some experience of caring for women with disability during pregnancy, childbirth or early motherhood. The population of relevant service providers from whom a sample was invited to attend a focus group included: general practitioners, midwives, obstetricians, neonatologists, paediatricians, allied health professionals, public health nurses and public health doctors, health care workers, family support workers, and psychiatrists/midwife specialists working in mental health within the maternity care setting.

4.6. Recruitment - individual interviews

In the light of the factors outlined above, and guided by the qualitative nature of the study, a key-informant/snowballing approach was employed. Access to

the population was via a number of routes including individual women with disabilities, posters advertising the study in 3 maternity hospitals, 2 of which had a specialist service for women with mental health difficulties, and a national advertising campaign using the specialist magazines, newsletters and websites of key representative bodies including:

- Schizophrenia Ireland (now SHINE)
- Federation of Voluntary Bodies of Ireland
- Spinal Injuries Ireland
- Irish Wheelchair Association
- MS Ireland
- Inclusion Ireland
- Frontline
- Women Together Network
- Aware
- GROW
- Irish Advocacy Network
- National Council for the Blind of Ireland
- Irish Deaf Society

Information about the study was also submitted and published in Medicine Weekly and the Sunday Times. Trinity College Dublin issued a press release on 10th March 2008, which resulted in the study being advertised and promoted in the national press and on radio including in the Irish Times and Irish Independent, on Newstalk, East Coast Radio, and Outside The Box an RTE One radio production. Information on the study was also posted on a web-link from the TCD homepage.

Posters and information packages were sent to regional support groups linked with all the above national groups and agencies, and to:

- Irish Guide Dogs for the Blind

- DeafHear
- Irish Deaf Women's Group
- Women with Disabilities in the West
- Rehab Ireland
- Family Resource Centres
- All regional Health Service Executive (HSE) Health Centres
- 200 general practitioners and public health nurses.

An advertisement campaign aimed specifically at women with intellectual disability was also circulated via intellectual disability list-servs, including that provided by the National Council for the Professional Development of Nursing and Midwifery. This was supplemented by posting or emailing advertisements to more than 100 services, self-advocacy groups and individuals across the country. Snow-ball sampling was also employed as a means of maximising exposure. Links were formed with the psychiatric teams and medical social workers in the 2 of the 3 study sites, which provided mental health specialist services. These persons acted as gatekeepers and assisted with the recruitment of women with mental health difficulties during pregnancy and the postnatal period. Members of the research team attended meetings of support groups around the country to promote the study and provide information to potential gatekeepers and participants. Study information was also posted on parenting websites including Rollercoaster, MagicMum and Aims Ireland.

An initial letter and information brochure (Appendix 3) was sent to all women who fulfilled the inclusion criteria, and contacted the team offering to take part. The information brochure (which had been reviewed by the National Adult Literacy Association, and was translated into Braille and an audio version where appropriate) informed potential participants of the purpose, process, potential benefits and harms, the availability of psychological support if upset occurred during the interview, data collection procedures, time commitment, voluntary participation, the right to withdraw without prejudice to care,

assurance of confidentiality (including in any publications associated with the study), researchers' contact details and an offer to answer any questions.

Those who indicated their willingness to be interviewed were contacted by a member of the research team, who answered any questions and arranged a suitable time and venue to meet and conduct the interview. Each participant was asked to sign a consent form prior to interview, consenting to be interviewed and the interview being digitally recorded, and a second consent form at the end of the interview consenting for data to be used in the study and publications (a copy of their consent form was given to each participant if they so wished). The demographic questionnaire was administered and completed at this time also.

4.7. Recruitment - focus group interviews with health professionals

A letter was sent to Directors of Nursing and Midwifery in the 19 publicly-funded maternity hospitals requesting them to nominate a person in the following positions – Director of Nursing/Midwifery, midwife, maternity care assistant, obstetrician, neonatologist, paediatrician, medical social worker, physiotherapist, psychiatrist, and midwife specialist in mental health to participate in a focus group discussion. Replies were received from 8 maternity units. Three maternity units furnished the names of the various health professionals, but 5 maternity units indicated that due to the Health Service Executive's embargo on travel and funding issues the Director of Midwifery, midwife and maternity care assistants would be unable to attend a focus group at this time. A reminder letter was sent to the remaining 11 maternity units requesting them to nominate persons in the various positions identified above.

The HSE's local health offices in each county were also consulted and they provided the contact details for general practitioners, public health nurses, social workers and physiotherapists employed in their respective primary

community care services. Information about the focus groups and sites where they were to be held was also disseminated to:

- Association of Occupational Therapists Ireland
- Society of Chartered Physiotherapists
- Irish Association of Social Workers
- Irish Practice Nurse Association
- Irish Association of Directors of Nursing and Midwifery
- Mental Health Nurse Managers Ireland
- National Network of Public Health Nurses
- Nurses working with Travellers.

A total of 6 focus groups were conducted. Four multidisciplinary focus groups were held, one each in Dublin, Donegal, Galway and Waterford. At least one representative from each discipline was invited to each group, and if unable to attend, a similarly suitable alternate was invited. Where possible, participants were purposively selected, with assistance from the key contact person in each area, to attend on the basis of a known openness to the support of women with disabilities, or a track record of developing services for such women. Once lists of names of selected representatives of each health professional group were provided, a letter of invitation and an information brochure was sent to each one, seeking their support and attendance (Appendix 3). Similar invitations were issued to other health professionals in the primary care services and, in total, over 600 letters of invitation were issued. In addition to the above, 2 disability specific groups, 1 intellectual disability and 1 mental health were held in Dublin and Donegal respectively. The intellectual disability focus group was held to gather some data from that area of care as there had been so few women included in that strand (section 4.6.3.).

A mental health-specific focus group was convened in the Donegal area to discuss the specialist mental health services and care provided for women

with mental health difficulties in the region. Participants in this group had been invited to the multidisciplinary focus group conducted in Donegal but they were unable to attend on the particular day the group was convened. However, they were eager to relay their experiences so the research team decided to conduct a specialist focus group on mental health. During the individual interviews it also emerged that this service was a good example of high quality care.

4.8. Challenges in recruitment - physical and sensory strands

The length of time it took to recruit participants to the physical and sensory strand of the study was considerable. Recruitment spanned 18 months and a 3-phased recruitment strategy was used. The critical feature was establishing a trusting relationship with the gatekeepers in the study sites and key worker/resource officers in the voluntary organisations and agencies. This relationship evolved from a partnership approach, and the purpose was to maximise the potential of recruiting participants for any strand of the study.

One issue which did arise was the importance of reinforcing the participants' right to anonymity and confidentiality, which proved to be particularly important in the hearing impairment strand of the study. The deaf community is a small, close-knit one and participants were concerned that when they recounted their experiences their identity could be readily deciphered. Meeting with key people in the deaf community, discussing and outlining the purpose and aims of the study was invaluable. Again, establishing a trusting relationship was critical, and it was this personal contact that yielded the most responses.

4.9. Challenges in recruitment – mental health strand

In relation to the women with mental health problems one issue did arise during the recruitment process. To meet the requirements of the Faculty of Health Sciences ethics committee in Trinity College Dublin a detailed information booklet was sent to women who expressed an interest in the

study. During the interviews some women expressed the view that the level of detail in the information booklet was off-putting and may have inhibited women from taking part, due to the mistaken belief that in their contribution they had to be very 'clever' or 'articulate'.

4.10. Challenges in recruitment – intellectual disability strand

In pursuance of its aim, this study sought to speak with women with intellectual disabilities regarding their experiences of the health services. The research team aimed to undertake 18 interviews with women who had intellectual disabilities. Six semi-structured interviews were to be conducted during pregnancy, 6 during the immediate post-natal period (up to 6 months), and 6 during early motherhood (6 months to 2 years). Following commencement of sampling, it quickly became apparent that this was an ambitious target that would be difficult to attain. The main reason underpinning this issue was not, however, related to the absence of potential participants, nor to any unwillingness on the part of such women to participate. It was, rather, due to significant difficulties which were encountered in actually getting the accessible information on the study to the women, despite widespread advertisement via formal and informal channels (section 2.4.6. above).

To open the study to a larger population, an amendment to the initial ethics approval was agreed by ethics committee and the NDA. This allowed a change to the early motherhood criterion from 2 to 4 years, a change which in fact did not result in any increase in volunteers. It was, however, through an unexpected route that 3 participants finally came forward and contributed their views. This arose from a discussion during one of the focus groups with health professionals, where one of the attendees knew of a Crisis Pregnancy Agency-funded service for women with special needs, including intellectual disability.

Other researchers have reported similar issues and challenges in attempting to access people with intellectual disabilities, especially when researching sensitive topics (Stalker, 1998; Lennox et al, 2005; Simpson et al, 2006). In an attempt to understand the above difficulties, and in view of the importance of obtaining experiences of women with intellectual disabilities, it was agreed that a number of further actions would be pursued. This included the organisation of a focus group with the senior management of services. This was arranged via the National Federation of Voluntary Bodies, and provided some contextual understanding of the issues pertaining to women who are service users becoming pregnant. It was also agreed that all service providers would be contacted via the National Federation of Voluntary Bodies to ascertain whether they are providing a service to any women who meet the revised inclusion criteria; any such notification being followed up by enquiry with the service as to whether the woman would be interested in knowing more about the study. No such notification was received. Finally, it was agreed that the research team would engage with groups such as Inclusion Ireland and self-advocacy groups to arrange a study team presence at self-advocacy conferences across Ireland in early 2009 to attempt to recruit interested women at those events. Despite dissemination of information by word of mouth and leaflets at such events, no contacts followed this.

Two months before the end of the study, one service met with the research team, discussed the study proposal, and approved a submission to their ethics committee. Approval from the committee was expedited, information was circulated and one woman with an intellectual disability agreed to take part in an interview.

4.11. Challenges in recruitment - focus group interviews with health professionals

There were no real challenges experienced when recruiting participants for the focus group discussions, although the planning and organising of each group took 12 weeks. Arranging and booking the venue was uneventful,

thanks to the hospitality of the Director of Midwifery, as the focus group discussions were held in a maternity unit/hospital in each region. However, locating and obtaining a list or directory of service providers in each county was difficult so the team reverted to the telephone directory and contacting the Health Service Executive's local health offices in each county, whose help and assistance was invaluable. They provided the contact details for the general practitioners, public health nurses, social workers, managers of disability services and physiotherapists employed in the primary community care services in each of their respective areas. In addition to the unit/hospital based practitioners, health professionals working in the 19 publicly-funded maternity units/hospitals were also invited to participate in the focus group discussions.

5. Sample size

5.1. Individual interviews

The proposed sample size was 90, with 30 interviews at each of the 3 stages of pregnancy, childbirth and early motherhood. Each of the 5 specific disability strands was to have 6 women included at each of the 3 time periods, a total of 18 in each strand.

In the main study, 89 women volunteered to participate but 11 did not meet the criteria and were not interviewed; one was excluded because of a pending legal case, 3 because their children exceeded the age criteria and 7 because they had no disability or mental health difficulty. Thus, 78 women who faced ability challenges were interviewed, 18 each in the physical, vision and hearing impairment groups, 20 in the mental health and 4 in the intellectual disability group. One woman from the mental health strand was interviewed 3 times, at her request, and one from the intellectual disability strand was interviewed twice (chapter 1, section 1.2.), which resulted in a total of 81 interviews. Twenty (25%) of the interviews were conducted during pregnancy,

30 (37%) during the immediate postnatal period and the remaining 31 (38%) in early motherhood.

5.2. Focus group interviews with health professionals

A total of 656 people were invited to participate in the 4 multidisciplinary focus groups around the country, resulting in the attendance of 19 people (Table 7). Invitations were sent to 227 people to participate in the Dublin focus group; 40 persons sent their apologies and nobody attended on the particular day. A second focus group was arranged for Dublin, 92 health professionals were invited, 11 people sent their apologies and 9 people attended. Information on numbers attending the remaining 3 multidisciplinary focus groups are included in Table 8. Where key informants indicated that they were interested in taking part but were unable to attend the group on the day chosen, telephone interviews were undertaken (n=2). Two people also provided information by e-mail.

Table 7 Number invited and attending the 4 multidisciplinary focus groups

	Galway	Dublin (1 st)	Dublin (2 nd)	Donegal	Waterford	Total
Invited to participate	97	227	92	133	107	656
Sent apologies	14	40	11	12	30	107
Attended	2	0	9	6	2	19
Total	2 (2.1%)	0	9 (9.8%)	6 (4.5%)	2 (1.9%)	19 (2.9%)

5.3. Focus group interviews with key personnel in the intellectual disability services

Six people were invited to participate in the focus group in Dublin, 1 sent apologies and 4 attended. A request was sent to intellectual disability service

managers in another area, to arrange a second focus group, without response within the study's timeline.

5.4. Focus group interviews with key personnel in the mental health sector in Donegal

Three people were invited to participate in the mental health focus group held in Donegal, and all 3 attended.

5.5. Total health professional sample size

In total, 26 people attended a focus group, 2 were interviewed by telephone and 2 contributed their response by e-mail (total 30). The breakdown of types of personnel included are shown in Table 8, with midwives, including Directors of Nursing and Midwifery, making up the largest single professional group involved (n=14, 47%).

Table 8 Number and type of personnel participating in interviews/e-mails

Personnel	Number (%)
Midwives	5 (17%)
Maternity care assistant	3 (10%)
Obstetrician	1 (3%)
Paediatrician	1 (3%)
Medical social worker	2 (7%)
Physiotherapist	2 (7%)
Psychiatrist	0
Directors of Nursing/Midwifery	5 (17%)
Mental health specialists	4 (13%)
Public health nurses	3 (10%)
Intellectual disability specialists	4 (13%)
Total	30

6. Data collection

6.1. Pilot study

A small pilot study of the individual interviews, involving 4 women (2 women with a physical disability, 1 with a vision impairment and 1 with mental health difficulties), took place. The contact methods, consent procedures and draft interview schedule were tested and researchers developed familiarity with the tools and process. Small changes were made to the interview schedule in preparation for the main study. In general, data from this pilot were not used in the final analysis, but one exemplar is quoted from the woman with a mental health difficulty as her experience added useful information to the findings.

6.2. Main study - demographic questionnaire

Demographic data (age, education, ethnicity etc.) were, with participants' consent, collected at the first interview to assess the socio-economic and geographical spread of participants.

6.3. Main study - semi-structured interviews

A flexible interview guide, developed from a comprehensive literature review, and modified in response to individual and group specific needs, was used (Appendix 4). Positively phrased open questions, paraphrases and prompts were used in addition to elicit maximum information from the women and seek clarity.

Interviews were conducted by team members, all of whom were experienced researchers with specific expertise in the areas of midwifery, mental health and intellectual disability, and were digitally recorded (with the women's consent) and transcribed. The face-to-face interviews provided high-quality, in-depth data, with rich, personal detail.

Women were interviewed in their own homes or at an agreed, accessible venue (hotel, health centre, maternity centre etc.) at a time of their choosing. The duration and format was woman-led and interviews lasted from 30-90 minutes, with a mean of 54.83 minutes, (SD15.60). The language used was adapted to be understood by the individual. Communication aids, as appropriate, included: written, Irish Sign Language, symbols and pictures. Women with a hearing impairment were offered the opportunity to have a sign language interpreter present for the duration of the interview and 9 women availed of this opportunity. Each woman was interviewed once but women who were pregnant at the point of recruitment were invited to participate in subsequent interviews either within 6 months of the birth or 2 years following the birth.

The interviews commenced with a brief re-introduction of the topic and obtaining written consent from the participant. Then the opening question was asked and the interview continued and was led by the participant. Subsequent interviews were informed by ongoing data collection and analysis (Glaser, 2005).

6.4. Main study – focus group interviews with health professionals

A flexible interview guide, developed from the literature and policy document reviews, and modified in response to the results of the telephone survey of all maternity hospitals (Begley et al, 2009b), was used (Appendix 5). Positively phrased open questions, paraphrases and prompts were used to elicit maximum information and seek clarity from the participants. Attention was paid to the participants' non-verbal cues to ensure they were comfortable and the moderators ensured that all had the opportunity to take part in the discussion

Six focus groups were conducted, lasting from 60 minutes to 90 minutes (mean 64 minutes, SD 5.47minutes). The venues were all located in maternity units/hospitals in the different regions and light refreshments were offered to

participants on arrival. The seating was arranged in a circle to maximise participation, and the recording device was placed in the centre. The discussion commenced with an icebreaker, a brief introduction from the researchers and participants, a reminder of the topic and purpose of the session and obtaining written consent from all participants. The opening question was then asked and the discussion continued, with prompts and/or comments posed by the researchers as necessary. When all components of the interview guide had been covered, the moderator asked for any last comments and then drew the session to a close, thanking all participants for their contributions. Follow-up telephone interviews were conducted with some key individuals who were unable to attend the focus groups, and other participants gave their views on the draft findings of the focus groups by e-mail.

7. Data analysis

All data from the individual interviews and focus groups were transcribed in full and any names that could identify the participant were removed. To ensure accuracy during the transcribing process the digitally recorded interview and written transcript were listened to, and read, simultaneously a number of times. The computer software package NVivo 8 was used to assist in the management of the qualitative data and SPSS (Statistical Package for Social Scientists) to conduct descriptive analysis on the demographic data. Written transcripts were examined systematically, and coded line by line. Categories of analysis were developed, from which the main themes emerged. When a number of interviews were completed from each strand of the study, the transcripts were examined by other members of the research team. Themes emerging following this analysis were then compared to those that were generated by the research assistants, in the process of peer debriefing. The themes were generally consistent and consensus was reached.

8. Rigour

The methods used to enhance the robustness of the study included using data collection from multiple sources, the constant comparative method process (comparing each interview with previous interviews, and each emerging category with previous ones, which ensures that new data collection is more targeted as the process continues), and the use of women's narratives to substantiate claims made about data (Beck, 1992; Jasper, 1994). 'Negative' case analysis (highlighting any comments that are in disagreement with the prevailing trend) and peer debriefing (disinterested researchers reviewing transcripts 'blind' and comparing with the initial researcher's view) (Denzin and Lincoln, 2005; Holloway and Wheeler, 2002) were also employed. In keeping with the idea of women as experts in, and owners of, their own experience, the emerging themes, interpretations and a synopsis of the final report were sent to all women and focus group participants, if they requested it at the time of interview. Reliability (or auditability) was achieved by inclusion of a systematic account of examples of the data analysis process (Hall and Gallery, 2001) in the appendices of this report (Appendix 6).

9. Ethical issues

9.1. Introduction

The involvement in this study of perceived vulnerable groups of people required particular consideration. It is acknowledged by the research team that avoidance of harm requires the researcher to strike a balance between the rights of the women, the risk of exploitation and the wider purposes of the research. It is argued that involving those most affected by an issue in qualitative research is an ethically appropriate way to proceed, as it promotes their interest by maximising autonomy in the research process and illuminates aspects of care that might otherwise be hidden.

9.2. Ethical approval

Ethical approval for the study was received from the Research Ethics Committee of the Faculty of Health Sciences, Trinity College Dublin on 9th November 2007. In addition, ethical approval was required and obtained from the 3 study sites.

9.3. Management of ethical issues

9.3.1. Protection of participants

All team members conducting individual interviews had obtained the usual Garda clearance checks required for health professionals, particularly in relation to child protection issues and were bound by national and international codes of good practice in research, and by professional standards within nursing and midwifery. In addition, all interviewers were provided with appropriate disability equality training prior to undertaking the relevant interviews. The rights and dignity of women were respected throughout by adherence to models of good practice related to recruitment, voluntary inclusion, informed consent, privacy, confidentiality and notice of withdrawal without prejudice.

The prevention of psychological harm and the physical well-being of the women were also considered in all aspects of the study. At all times their well-being took priority over the research study – if a participant became upset, the interview was stopped and only continued if the participant preferred to continue. In addition, the name and contact details of people within the service who were willing to give follow up emotional support were given to women, if required, in addition to an information sheet of contact details for support groups, services, web-site information etc., relevant to their particular circumstances. The team had access to a registered clinical psychologist who acted as a mechanism of referral for any woman who might require such a service; this service was not, in fact, required.

9.3.2. Informed consent

Consent was viewed as an ongoing process, which was re-negotiated at all stages of the interview process. Each woman partaking in the individual interviews was asked to sign a consent form prior to the interview, consenting to be interviewed, the interview being digitally-recorded and for the data to be used in publications arising from the study. A copy of their consent form was offered to all participants and given to those who wished to keep it. The same process was followed for all participants in the focus groups. Ground rules such as group confidentiality were also negotiated at the start of the focus group interviews.

9.3.3. Confidentiality

The recordings, transcripts and questionnaires were given code numbers, prior to submission to the transcriber (who also signed a confidentiality agreement). The code numbers were employed to protect the identity of participants in the final report. The master list of participants' names with these numeric identifiers was stored securely away from all other data. Data held on computer were password protected and stored in accordance with the Data Protection (Amendment) Act 2003.

9.3.4. Specific issues for women with intellectual disability

It was accepted that women with intellectual disabilities might wish to be accompanied by an advocate, to facilitate them in arriving at an informed decision regarding participation; all 4 of the participants availed of this opportunity. Women and their advocates were informed of the passive role of the advocate once consent was obtained. It was recognised that some women with intellectual disabilities might benefit from counselling services as a result of issues, such as the baby being taken from them, that could emerge during the course of the research process. The research team ensured that an appropriate counselling service was available for women with intellectual disabilities, and each woman was informed of the availability of this service

prior to interview. None of the women required this service following interview. The research was conducted at all times in terms that women understood.

9.3.5. Safekeeping issues for researchers

The usual 'lone researcher' safety steps were taken for all interviews (researcher carries a mobile, another person is aware of their whereabouts, researcher 'calls in' prior to and at the end of the interview). Psychological support in the form of debriefing was available for all researchers and the transcriber, if it was necessary.

10. Conclusion

The study began on 10th March 2008 and recruitment ceased on 10th November 2009, with 78 women included. A total of 81 individual interviews, 4 focus groups with multidisciplinary health professionals, one with mental healthcare professionals and one with key personnel in the intellectual disability services were undertaken.

Appendix 3 Participant information

3a. Letter to women expressing a willingness to participate in interviews

Dear

Thank you for your telephone call and for offering to participate in this study. The study will look at the strengths and weaknesses of Ireland's public health services for women with disabilities during pregnancy, childbirth and early motherhood. Your support will help us to ensure that we carry out the study as effectively as possible.

The enclosed information booklet will give you more details about the study. I am also attaching a consent form, which you should fill out and return to me in the enclosed stamped addressed envelope.

If you need any further information about the study or if anything in this letter is unclear, please contact me on the telephone number or email address provided below and I will be happy to discuss any details with you.

I look forward to hearing from you and will be in contact with you again soon.

Yours sincerely,

Denise Lawler

Denise Lawler
School of Nursing and Midwifery,
Trinity College Dublin,
24 D'Olier Street,
Dublin 2
Telephone: 086 3789758
Email: lawlorde@tcd.ie

3b. Letter to Director of Nursing and Midwifery to nominate persons for focus group

Re: A study exploring the strengths and weakness of the publicly funded health services for women with disabilities during pregnancy, childbirth and early motherhood.

Dear

As you are aware a team in Trinity College Dublin is undertaking a research study with the specific aim to explore the strengths and weaknesses of the publicly funded Irish health services provided to women with disabilities during pregnancy, childbirth, and early motherhood.

There are five strands to the study:

1. Physical disability
2. Hearing impairment/deaf
3. Vision impairment/blind
4. Intellectual disability
5. Mental health service users

Over the past number of months we have conducted semi structured interviews with women from the five different strands to ascertain their experiences when accessing the publicly funded health services during pregnancy, childbirth and early motherhood. We have also conducted a telephone interview with all the publicly funded maternity hospitals in Ireland, to identify the policies that govern service provision for women with disabilities during pregnancy, childbirth and early motherhood. Thank you for participating in the telephone interview. We are now embarking on the third phase of the study, inviting health professionals to participate in a focus group discussion.

The aims of the focus group are

- to ascertain the views of health professionals on the quality of current service provision for women with disabilities and
- to identify how future services can meet the needs of women with disabilities.

To ensure geographical representation the focus groups will be held in four different locations - Dublin, Galway, Donegal and Waterford. The duration of the focus group discussion will be approximately 1 hour. I am writing to invite you to participate in the focus group located nearest to you and also to nominate a person ideally, with an interest in the area of women with disabilities, in each of the positions identified in the attached list. Once I receive the names I will write to the person(s) and formally invite time to participate in the focus group.

Please complete the attached list with the name of the nominated person(s) and return it, in the enclosed stamped self addressed envelope, to Denise Lawler, School of Nursing and Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2.

Thanking you in anticipation.

Denise Lawler
Tel: 086 3789758
Email: lawlerde@tcd.ie

3c. Letter to participants inviting them to participate in the focus group

Re: A study exploring the strengths and weakness of the publicly funded health services for women with disabilities during pregnancy, childbirth and early motherhood.

Dear

A team in Trinity College Dublin is undertaking a research study with the specific aim to explore the strengths and weaknesses of the publicly funded Irish health services provided to women with disabilities during pregnancy, childbirth, and early motherhood.

There are five strands to the study:

1. Physical disability
2. Hearing impairment/deaf
3. Vision impairment/blind
4. Intellectual disability
5. Mental health service users

Over the past number of months we have conducted semi structured interviews with women from the five different strands to ascertain their experiences when accessing the publicly funded health services during pregnancy, childbirth and early motherhood. We have also conducted a telephone interview with all the publicly funded maternity hospitals in Ireland, to identify the policies that govern service provision for women with disabilities during pregnancy, childbirth and early motherhood. We are now embarking on another phase of the study, inviting health professionals to participate in a focus group discussion.

The aims of the focus group are

- to ascertain the views of health professionals on the quality of current service provision for women with disabilities and
- to identify how future services can meet the needs of women with disabilities.

To ensure geographical representation the focus groups will be held in four different locations - Dublin, Galway, Letterkenny and Waterford. The duration of the focus group discussion will be approximately 1 hour.

I cordially invite you to participate in the focus group located in the [***name of venue, geographic location and time here***]. Light refreshments will be provided. Enclosed is further information about the focus group including the questions that will frame the discussion. Please let me know if you will be attending/or will not be attending the focus group. I can be contacted via the telephone number or email address provided.

Yours sincerely,

Denise Lawler
Tel: 086 3789758
Email: lawlerde@tcd.ie

3d. Poster for All Strands

Mums & soon to be Mums...

tell us your experience

Are you interested in talking about your experience of maternity and early motherhood services in Ireland?

DO YOU HAVE ANY OF THE FOLLOWING?

- Blind/vision impairment
- Deaf/hard of hearing
- Physical disability
- Intellectual disability
- Experience of mental health services
- Are you a member of any of these groups? ▶▶▶

IF SO

- Are you over 18 years?

And

- Are you pregnant?
- Have you had a baby in the last 2 years?
- We would like to hear your experiences

WHAT IS THE STUDY ABOUT?

The study will provide valuable information about women's experiences and may improve maternity and childhood services in Ireland

For further information, please call: Denise Lawler

Phone: 086 3789758/ Email: lawlerde@tcd.ie

This study is funded by the National Disability Authority (NDA)

School of Nursing and Midwifery
Trinity College Dublin

3e. Information Booklet for Women

Mums and soon to be Mums ... tell us your experience

Are you interested in talking about your experience of maternity services in Ireland?

Title of study

An exploration of the strengths and weaknesses of the publicly funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood.

Why are we doing this study?

We set up this study to look at the strengths and weaknesses of Ireland's public health services for women with disabilities during pregnancy, childbirth and early motherhood. As little is known about your experiences of health services – both in Ireland and throughout the world – we hope to increase our knowledge of such services through this study, so that we can help to improve health and maternity services for women with disabilities.

Who can take part in this study?

We would like to talk to you if you have a disability and are pregnant or have had a baby in the past six months or two years. We will be asking you to tell us about your experiences of the public health system during pregnancy, childbirth or early motherhood. To take part in the study, you must be aged 18 years or over. We would like to hear from women with one of the following:

- a sight problem;

- deaf/hard of hearing;
- a physical disability;
- a mental health difficulty;
- an intellectual disability.

How do I take part?

If you agree to take part in the study, we will ask you to sign a consent form, giving us permission to interview you for the study. We will interview you face-to-face in your home or at another suitable location. The interview will last no longer than one hour. We will ask you to tell us about your experiences of the public health services during pregnancy, childbirth or the early stages of motherhood. We may ask you to take part in more than one interview. All interviews will be recorded to make sure that we get the best account of your views and experiences. You can ask for a copy of this recorded interview if you agree to take part in the study. We hope to use the information from the interviews to put together a report outlining your needs and views.

Note: If you are hard of hearing, you will be interviewed through sign language or in written form.

Do I have to take part in the study?

You do not have to take part in the study if you do not want to. We won't ask you to give a reason if you choose not to take part and your care will not be affected. If you agree to take part, you can pull out of the interview at any stage without giving any reason. You can also refuse to answer any question(s), turn the tape off, or ask to stop the interview at any time.

Will my privacy be protected?

We will make sure that all of the information you give will be kept totally private and we will not tell anyone that you took part in the study. Your name, details or any other information that might reveal your identity will not appear anywhere in the report resulting from this study. Your name will not even appear on the tape of your interview; instead, we will label this with a code number.

What are the benefits of taking part in the study?

You will not be paid for taking part in this study. However, we hope that the knowledge we gain from this study will give us a better understanding of your experiences and those of other women. This will, in turn, help us to improve the quality of health services for you and others in the future. You may also enjoy telling your story and gain knowledge or information through discussing your experience with a health professional.

Permission to carry out the study

This research has been granted ethical approval from the Faculty of Health Sciences, Trinity College, Dublin.

What should I do next if I decide to take part?

If you wish to take part in the study after reading this information leaflet, please fill out the attached form. The form will ask you for your name and contact details and to tell us whether or not you will be taking part in the study. If there is a particular time at which you would like us to contact you, please write this on the form. After you return the form in the envelope provided, we will contact you to discuss arrangements.

Where can I get further information?

If you need any further information or if you do not understand anything in this information sheet, please

contact us and we will be happy to discuss or explain any of the details.

For further information, contact:

Denise Lawler
School of Nursing and Midwifery,
Trinity College Dublin,
24 D'Olier Street,
Dublin 2

Telephone: 086 3789758

Email: lawlorde@tcd.ie

Thank you for taking the time to read this information.

This study is funded by the National Disability Authority

3f. Consent form for face-to-face interview(s)

TITLE OF THE RESEARCH STUDY:

To explore the strengths and weaknesses of publicly funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth, and early motherhood.

RESEARCHER'S CONTACT DETAILS:

Ms Denise Lawler, Telephone Number: 086 3789758, E-mail :
lawlerde@tcd.ie

BACKGROUND AND PROCEDURES:

In Ireland and internationally little is known about disabled women's experiences of health services. This research is attempting to fill the gap in knowledge, by providing information, which may impact on future development of health and maternity services. The study will involve interviewing service users.

The study involves a face-to-face interview conducted in your home or a venue accessible for you. The interview will be about 45-60 minutes and will be conducted at a time convenient for you. The objective is to hear your views and opinions and to listen to your experiences. You will be asked a range of open-ended questions, which you are free to answer, and or not answer in whatever way you choose. If you agree to be interviewed we would like to tape record the interview, so we can listen to it afterward, to ensure that we represent your views and experiences as completely as possible. The interview will be held at a time and location convenient to you and of your choosing.

DECLARATION (Please read and sign if you agree):

I have read the study information sheet and this consent form.

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential.

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

I have received a copy of this agreement and I understand that the results of this research may be published.

I understand I may withdraw from the study at any time.

PARTICIPANT'S NAME (Block Capitals):.....

CONTACT NUMBER:

PARTICIPANT'S SIGNATURE:.....

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this study to the persons named above, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the person named above understood my explanation and has freely given informed consent.

Investigator's Signature..... **Date**.....

For Investigator's Use Only

Participant Code: -----

3g. Consent form for focus group

DECLARATION (Please read and sign if you agree):

I have read the study information sheet and this consent form.

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.

I understand that all information collected in this focus group will be treated as confidential and that my identity will remain confidential.

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

I have received a copy of this agreement and I understand that the results of this research may be published.

I understand I may withdraw from the study at any time.

PARTICIPANT'S NAME (Block Capitals):.....

TITLE/POSITION:.....**CONTACT NUMBER:**

PARTICIPANT'S SIGNATURE:.....**Date:**.....

Statement of investigator's responsibility: I have explained the nature and purpose of this study to the persons named above, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the person named above understood my explanation and has freely given informed consent.

Investigator's Signature**Date**.....

Appendix 4 Interview schedule for individual interviews

1. Thank you for taking part in this study, are you happy to proceed with the interview?
2. Could you tell me about your disability?
3. Can I explore your experiences of the maternity services? (during pregnancy, childbirth and early motherhood)
 - a. What pregnancy is this? How many children do you have?
 - b. Could you discuss the background to your pregnancy?
(**prompt:** planned/ unplanned)
 - c. How was /who confirmed your pregnancy?
 - d. What model/type of antenatal care did you have? (**prompt:** CANC, hospital only, home birth, Domino)
 - e. Did you experience any challenges getting to and from the hospital, GP clinic, health service?
4. Can you tell me about your **first antenatal visit**?
 - i. Can you tell me about the infrastructure/physical environment (**prompt:** access, challenges)
 - ii. Can you tell me about the interaction with the health professionals (**prompt:** attitudes you may have come across, communication methods, interpersonal skills)
 - iii. Can you tell me about the information you received?
 - iv. Was an assessment of needs conducted? (**prompt:** specific needs discussed and/or identified)
 - v. Were you referred to other departments/professionals?
(**prompt:** physio, MSW, patient services)
5. Can you tell me about your **subsequent antenatal care**?
 - i. Model of care/where did you have the care? hospital, Domino, ETH, homebirth
 - ii. How often were your visits?
 - iii. Did you experience any problems getting to and from the hospital, GP clinic, health clinic?
 - iv. Can you tell me about the infrastructure/physical environment ? (**prompt:** access, challenges)
 - v. Were you orientated to the environment?
 - vi. Can you tell me about the waiting area and the call/appointments system?

- vii. Can you tell me about the interaction with the health professionals (**prompt:** attitudes you may have come across, communication methods, interpersonal skills, awareness of disability and related issues)
 - viii. Can you tell me about any investigations you had? (**prompt:** scan, hearing fetal heart, screening)
 - ix. Were things explained to you?
 - x. Were findings explained to you?
 - xi. Did the health professionals appear knowledgeable about your disability?
 - xii. Did the health professionals collaborate with each other? (**prompt:** obstetricians, neurologists, midwives, physiotherapists, prosthetic nurse)
 - xiii. Do you think your disability took precedence over your pregnancy?
 - xiv. Were your specific needs determined?
 - xv. Were your specific needs addressed?
 - xvi. Were you referred to other departments/professionals? (**prompt:** physio, MSW, anaesthetist)
 - xvii. Was a birth plan discussed and developed?
 - xviii. How did you keep in contact with the hospital? (**prompt:** telephone, email, text, fax, minicom)
6. Can you tell me what communication aids did the HPs use? (**prompt:** sign language interpreter, pictures, Braille)
7. Can you tell me about the information you were provided with?
- i. Format (**prompt:** visual/CD, audio, written, Braille)
 - ii. Explanation
 - iii. Antenatal classes
 - Where were they provided?
 - Were they accessible?
 - Did they address your specific needs?
 - Exchange of information – appropriate strategies used?
8. Did you receive any practical assistance? (**prompt:** to get to antenatal clinic, midwifery staff, portering staff)
9. Did you receive adequate reassurance? (**prompt:** scan if VI, fetal heart if HI)

10. Can you tell me about your experiences during **childbirth**?
- i. Model of care? hospital, Domino, home birth
 - ii. How did you recognise you were in labour?
 - iii. Did you have a birth plan?
 - iv. Can you tell me about the infrastructure/physical environment ?(**prompt:** access, challenges)
 - v. Were you orientated to the environment?
 - vi. Can you tell me what communication aids did the HPs use? (**prompt:** sign language interpreter, pictures, Braille)
 - vii. Were your specific needs determined?
 - viii. Were your specific needs addressed?
 - ix. Choice (**prompt:** pain relief, positions in labour)
 - x. Issue of consent (VI, HI)
 - xi. Monitoring (**prompt:** fetal heart, CTG)
 - xii. Support and assistance
 - xiii. Reassurance
 - xiv. Did the health professionals appear knowledgeable about your disability?
 - xv. Did the health professionals collaborate with each other? (**prompt:** obstetricians, neurologists, midwives, physiotherapists, prosthetic nurse)
 - xvi. Do you think your disability took precedence over your pregnancy?
11. Can you tell me about your experiences during the **postnatal period**?
- i. Model of care – hospital, Domino, ETH, home birth
 - ii. Can you tell me about the infrastructure/physical environment ?(**prompt:** access, challenges)
 - iii. Were you orientated to the environment?
 - iv. Can you tell me about the interaction with the health professionals (**prompt:** attitudes you may have come across, communication methods, interpersonal skills, awareness of disability and related issues)
 - v. Did the health professionals appear knowledgeable about your disability?
 - vi. Did the health professionals collaborate with each other? (**prompt:** obstetricians, neurologists, midwives, physiotherapists, prosthetic nurse)
 - vii. Do you think your disability took precedence over your new role as mother/parent?
 - viii. Were your specific needs determined?

- ix. Were your specific needs addressed?
- x. Practical support and assistance received?
- xi. Information received/quality of and format?
- xii. Issue of consent (VI, HI)
- xiii. Parenting skills (**prompt:** feeding, bathing, bonding)
- xiv. Reassurance
- xv. Were you referred to other departments/professionals?
(**prompt:** physio, MSW, PHN)
- xvi. Can you tell me about preparing for going home?
 - Links with voluntary/community agencies?
 - Information about support aids?
 - Follow up for mother and baby (**prompt:** six week examination)
 - Screening and immunisation programme (**prompt:** breast examination, cervical screening, PKU, immunisations)

12. Can you tell me about your experiences with the Public Health Nurse?

- i. Access to health centre
- ii. Knowledge
- iii. Communication
- iv. Support
- v. Reassurance
- vi. Parenting skills/issues around ability to parent?

Appendix 5 Interview schedules for focus groups with health professionals

5a. Interview schedule for focus group with all health professionals

Good afternoon, and welcome to our meeting. First of all we would like to thank you all for coming today and we look forward to hearing your contributions. My name is I am a lecturer at Trinity College Dublin, and I am currently involved in a study commissioned by the NDA, exploring the strengths and weaknesses of the publicly funded Irish health services provided to women with disabilities during pregnancy, childbirth, and early motherhood. With me today is a lecturer at Trinity College, Dublin.

You were asked to attend because you are the health professionals engaged in service provision for women with disabilities. Please feel free to share your point of view even if it differs from what others have said. There are no right or wrong answers but differing points of view.

Before we begin, can we establish some ground rules?

1. Please feel free to speak
2. One person should talk at a time
3. We will be recording the discussion, so that we can listen to it afterwards, to ensure that we represent your experiences and views accurately. If several people are talking at the same time, the tape will be unable to capture the comments clearly
4. The session will be recorded and notes will be transcribed during the session

The duration of the focus group discussion will be approximately 1 hour.

We would like you to consider the following questions for each of the five different strands (physical disability, hearing impairment; vision impairment; intellectual disability and mental health service users).

Questions

Opening Question:

Let's find out some more about each person. Can you tell us your name and background?

Key Questions:

1. What from your professional perspective are the important needs of women from each of the different strands (physical disability, hearing impairment, vision impairment, intellectual disability and mental health service users) during pregnancy, childbirth and early motherhood?
2. What are your views on the quality of the services currently available to meet the needs of women and their families from all five strands (physical disability, hearing impairment; vision impairment; intellectual disability and mental health service users) including:
 - Information
 - Practical support
 - Psychological support
 - Financial support
 - Family support
 - Participation, decision making and choice
3. What are the greatest challenges in delivering services for women and their families from all five strands (physical disability, hearing impairment, vision impairment, intellectual disability and mental health service users)?
4. How can these challenges be addressed?

Summary and Conclusion

To conclude can we recap on the main issues that have been raised/discussed?

- What are the three key issues in current service provision for each strand?
- What are the three key issues in future service provision for each stand?

- Of all the issues identified is there one that you would consider important in the provision of services for women with a disability during pregnancy, childbirth and early motherhood?

Finally

- Is there anything else of importance/relevance that you would like to add?

5b. Interview schedule for focus group with service providers from intellectual disability strand

Purpose

To explore service managers' perspectives on public health services for women with intellectual disability who are pregnant, who have recently given birth or who are in the early stages of motherhood.

Objectives

To find out:

1. Services' experiences of pregnancy, childbirth and early motherhood within their service users;
2. The specific issues that pregnancy and early motherhood pose for intellectual disability services.
3. Perceptions on access to, and responsiveness of, public health services for women with intellectual disability who are pregnant, who have recently given birth or who are in the early stages of motherhood.
4. Perceptions on continuity of care between intellectual disability services and health services for service users who are pregnant, who have recently given birth or who are in the early stages of motherhood.
5. Ideas to ensure that the needs of women with intellectual disabilities who are pregnant, who have recently given birth or who are in the early stages of motherhood are appropriately addressed.

Welcome and Introduction

Opening lines

Please feel free to share your point of view even if it differs from what others have said. There are no right or wrong answers but rather differing points of view.

Before we begin, let me share some ground rules. Please speak up clearly. Only one person should talk at a time. I will be recording the session because I don't want to miss any of your comments, but, please note that all contributions will be anonymised and neither your identity nor the identity of your service will be associated with transcribed material.

The aim of the meeting is to explore service managers' perspectives on public health services for women with intellectual disability who are pregnant, who have recently given birth or who are in the early stages of motherhood.

The session, this afternoon, will last, at most, 90 minutes, and the NDA have graciously provided a light lunch afterwards. Let's begin! I have placed name cards on the table in front of you to allow us to remember each other's names.

Opening Question:

1. Let's find out some more about each person, by going around the room one at a time. So, tell us your name and something about your involvement in service provision.

Introductory Question:

1. As the NDA study has progressed, we have become aware of a significant number of women with intellectual disabilities receiving ID services that are or have been pregnant. Tell me about the occurrence of any such instances in your services.
2. What challenges have these occurrences posed for your service and how have you responded to them?

Key Questions:

1. (In relation to pregnancy, childbirth, early motherhood or in relation to women's health) To what degree have public health services been responsive to the women's specific needs? Was there easy access to such services?
2. What lines of communication exist between your services and the maternity services in your locality? Was there good continuity of care?
3. Some women with intellectual disabilities with children have suggested that, whereas the ID services were supportive, community social services placed significant strain on their parenting abilities, apparently expecting failure. What are your thoughts on this?
4. Can you put forward any ideas to ensure that the needs of women with intellectual disabilities who are pregnant, who have recently given birth or who are in the early stages of motherhood are appropriately addressed?

Ending Questions:

1. Of all the issues discussed, is there one that you consider to be of paramount importance in relation to the needs of women with ID being met?
2. The aim of this meeting was to explore service managers' perspectives on public health services for women with intellectual disability who are pregnant, who have recently given birth or who are in the early stages of motherhood. From the issues discussed, can you think of anything else of importance or anything that we have forgotten?

Summary & Conclusion

Appendix 6 Audit trail - example of first and second round coding of data

6a Data Analysis (First round coding – Literal Coding)

Pregnancy

Disability Strand	Text/Quote	Themes and subthemes [Literal Coding]
Physical Disability	<p><i>'The cerebral palsy ... to be honest I'm ok with it, I mean it has never really hindered anything I've done or, you know I've always you know managed, if I couldn't do something a certain way, I would figure out my own way of doing it'. (PD7)</i></p> <p><i>'Basically if affects the balance on the left side, everything on the left side is weaker, than what it would be on the right, it is more so the co-ordination than anything else'. (PD7)</i></p> <p><i>'As the pregnancy went on and I got bigger yeah it was a problem because the legs became very restricted in movement, as regards lifting and things like that and I often, which was quite frightening, I would often lose the power in my legs because she would sit on a nerve in the back so the legs would just go without a warning ... gone for maybe an hour, maybe 2, it could be half an hour, it could be 10 minutes it depends on herself (baby) and when she decided to move'. 'I became quite restricted in my own movements and things that I could do, well that I was able to do, that I couldn't do'.</i></p> <p><i>'I actually didn't find out I was pregnant until I was quite far along, I was 16, nearly 17 weeks before I found out I was pregnant, the reason for that being was I was always quite irregular in the menstrual cycle'. (PD7)</i></p>	<p>Theme 5. Disability Sub theme – <i>Acceptance and adaptability</i></p> <p>Sub theme – <i>Impact of pregnancy on disability</i></p> <p>Theme 1. Access to services Sub theme – <i>Barriers to diagnosis of pregnancy</i></p>

	<p><i>'My local GP was actually treating me for gastro-enteritis and didn't think to ask you know was I pregnant or you know look for a urine sample or anything like that. It was only myself, it kind of registered with me, I thought to myself well gastro-enteritis can't last for 3 weeks, 3 or 4 weeks, so it was just by accident I kind of went in and said to myself well I'll take the pregnancy test and I'll see what happens and it came out positive then'. (PD7)</i></p> <p><i>'I actually had a row with him (GP) over the phone, saying listen you have to come up, I wouldn't ask unless I really needed it. But previously I had 2 doctors out on call ...because I was really, really bad and I was getting sick and everything and I was hallucinating and everything else, I was really, really bad and they had given me injections and things and both of them had said oh its gastro enteritis it will be gone inside of a, well the vomiting will stop after the injection and that was it really'. (PD7)</i></p> <p><i>'Transport was a difficult thing, getting taxis to go into town early in the morning is very difficult, not a lot of them will go in because a) they will get caught in traffic and b) they won't get a run to bring them out again. So not a lot of them will go in'. 'Buses ... were quite difficult, with schedules and things, I often missed appointments, early appointments due to traffic and different things like that'. (PD7)</i></p> <p><i>'Yeah transport was the main problem, appointments were always made very earlier and it was difficult to kind of arrange some other time and when I didn't, I was kind of confronted with phone calls saying well you know why haven't you turned up and you know what is going on here and you've missed this appointment again, you know we can't keep re-scheduling, that was the kind of attitude now no matter how many times you try and tell them look it is difficult to get in, you kind of met with a blank wall'. (PD7)</i></p> <p><i>'The clinics are not in any way shape or form set up. You have a kind of production</i></p>	<p>Sub theme – <i>Barriers to diagnosis of pregnancy</i></p> <p>Sub theme – <i>Structural environment – transport</i></p> <p>Sub theme –</p>
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<p><i>line'. 'You can certainly get in the door but it's not very easy, these things certainly haven't been thought of really well'. (PD8)</i></p> <p><i>'There was ramps, ramps for people to come in with their buggies and that so that was fine. The accessible toilet wasn't great, it was really more it was big to allow a mother to bring a pram in rather than being a properly adapted toilet but with my husband with me I could use it but I wouldn't have been able to use it without him'. 'Not all the entrance doors are ... automated, so that's difficult which is definitely not the way it should be and you've got a heavy door, so you're trying to balance yourself and try and get the door open, so that's bad but if you come in the main entrance its automated'. (PD5)</i></p> <p><i>'... Parking in the (maternity unit) is a nightmare and there is a designated space but it's not policed and inevitably people park where they shouldn't'. (PD5)</i></p> <p><i>'One of the biggest problems I had all the way through the pregnancy and when I was in the hospital was having to climb up (on examination table/bed), I mean it's difficult enough when you are not pregnant to get from a wheelchair into something like that but, it's very often impossible. But certainly add the baby weight onto it, it's basically nuts. But yet I would have to get up and down off these things because they didn't have adjustable beds'. (PD8)</i></p> <p><i>'The examination couch was not height adjustable, just an old wooden couch'. (PD5)</i></p> <p><i>'Late at night I actually had to go in to have an emergency scan (woman had a bleed), but me not thinking and this being my first pregnancy, I went to the first hospital that was nearest, I went into (general hospital) and a nurse there actually, for want of a better word gave out to me, you know saying well this isn't a maternity hospital and you should have went to (maternity unit), to which my partner retaliated well excuse me I'm</i></p>	<p><i>Structural environment – antenatal appointments</i></p> <p>Sub theme – <i>Structural environment – antenatal clinic</i></p> <p>Sub theme – <i>Structural environment – antenatal clinic</i></p> <p>Sub theme – <i>Structural environment – antenatal clinic</i></p> <p>Sub theme – <i>Structural environment – antenatal clinic equipment</i></p> <p>Sub theme – <i>Structure of publicly funded health service</i></p>
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<p><i>not going to bypass one hospital to get to another one'. (PD7)</i></p> <p><i>'Basically getting it from the internet or, I asked, my mum has a friend and she has CP and she had a baby, she had 4 kids now, so I kind of sat with her and asked her a few things'. (PD7)</i></p> <p><i>'I was saying to him (doctor in maternity unit) ... can you explain that to me please, what are you talking about, I'll discuss it with you in a minute was the kind of and very sharp you know, kind of no I'm doing something and me you know worrying there is something seriously wrong (with baby), but the attitude I was confronted with was well I'm doing something, I'll get around to you when I'm ready to get around to you'. 'He was the only negative one I came across, that was fairly, you know my opinion is my opinion and I don't have to discuss it with you, if I don't want to, you know that kind of way'. (PD7)</i></p> <p><i>'He (GP) seemed kind of arrogant ...I had asked him to come up to the house because I couldn't move, I was really, really sick and he seemed to be well you know my dinner is on the table and that kind of attitude and I have to go home, I have had a surgery of patients all day'. (PD7)</i></p> <p><i>'I have to say ... the midwives were very good and they were very helpful. Yeah, they were quite helpful, I mean any questions I had as in regards to what was going to happen or pain wise or anything like that, they were always very open and very upfront, you know and very co-operative and very helpful, so there was no problem there with them, there was just the one, but you always get the kind of the one that will make things difficult for you'. (PD7)</i></p> <p><i>'Basically (H.P. name) said to us I help loads of disabled women to get pregnant but they've all had accidents which made them disabled, none of them had genetic</i></p>	<p>Theme 2. Appropriateness of services Sub theme – <i>Sourcing information</i></p> <p>Theme 3. Responsiveness of services Sub theme – <i>Interactions with health professionals</i></p> <p>Sub theme – <i>Interactions with health professionals - Reciprocity</i></p> <p>Sub theme – <i>Interactions with health professionals</i></p> <p>Sub theme – <i>Interactions with health professionals –</i></p>
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<p><i>impairments, so basically he was saying that if there was any risk, we couldn't guarantee that we wouldn't have a disabled child, he didn't want to know, that was pretty much it. Thankfully I'm a very stubborn person and I refused to let their prejudice impact on my life and also thankfully I have met some amazing people over the years'. (PD5)</i></p> <p><i>'He (doctor in maternity unit) didn't really tell me anything ... he was kind of another one rushing me up for scans this, that and the other'. (PD7)</i></p> <p><i>'Any information I got, I got myself. There was a leaflet given to me, just a leaflet on you know things you eat and things you don't ... any information I got, I got myself.' (PD8)</i></p> <p><i>'When you have CP and you're not, your mindset is on one thing and they (H.Ps) are contradicting you going on about something else, it is frightening. You are trying to grab these people and say well look and ask these kind of questions, well what is going to happen or you know what is going to be done or what are you doing to me or you know that kind of way. And it is quite frightening, especially when you can't get the time with them to say well listen this is the way I want things to go or this is more comfortable for me and when you are being met with a blank wall, as in regards to that it is scary, it is quite scary'. 'Rushed, you know questions were answered quite quickly and even then they weren't, I felt like I wasn't being listened to half the time. It's confusing and it is scary all at the same time'. (PD7)</i></p> <p><i>'In the hospital I wasn't believed, I wasn't listened to.' (PD8)</i></p> <p><i>'They (H.Ps) talked over me an awful lot of the time and even, no matter how many times you said hello you know I'm here, yeah I'm in the room, you know talking over me, it was still kind of very well, you know this has to be done with her and that has to be done with her, so it wasn't, it was very closed off'. (PD7)</i></p>	<p><i>Prejudice</i></p> <p>Sub theme - <i>Exchange of information - Disempowering</i></p> <p>Sub theme - <i>Exchange of information</i></p> <p>Sub theme - <i>Exchange of information - Disempowering</i></p> <p>Sub theme - <i>Exchange of information - Disempowering</i></p>
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	<p><i>'They (doctors maternity unit) kept saying to me, well we've had people that can't feel from below the waist and she kept referring to this not feeling from below the waist and no matter how many times I tried to tell her, she still referred back to, oh we have had many people that can't feel from the waist down. It was kind of like, yeah well you are telling us this but we are going to try this. They didn't seem to know ... much about my condition, if anything. It was kind of like they (H.P.s) were generalising'. (PD7)</i></p> <p><i>'I had to tell them (about the disability). I think in a way it's better because if they already have ideas they might have preconceptions that are not correct, so I think it was in a way better because it meant that I was the expert'. (PD5)</i></p> <p><i>'The physiotherapist had said, I was asking her questions, how will it affect the legs and the back and this that and the other and her answer to me was kind of like well I know as much about it as you do. I didn't get to see her much, I didn't get, I only got to see her twice I think throughout the whole pregnancy'. (PD7)</i></p> <p><i>'I kind of, I felt like surely to God I can't be the only woman with CP to have a baby, I'm not I know that, but that is the way it kind of felt. H.P. still generalise, they still don't seem to know an awful lot about it, which is frightening in a sense, because even though you are trying to explain things to them, they still generalise and they still you know, they weren't prepared to, well they were listening but it wasn't, it was kind of going in one ear and out the other'. (PD7)</i></p> <p><i>'My partner would have been there most of the time, so he would have been the main source of help there'. (PD5)</i></p> <p><i>'I was only referred to an ante-natal class towards the end, I mean in the last 2 weeks of the pregnancy which is absolute lunacy. I had enquired about it myself beforehand</i></p>	<p>Sub theme - <i>Communication with health professionals</i></p> <p>Sub theme – <i>Lack of health professional's knowledge re disability and needs</i></p> <p>Sub-theme – <i>Lack of health professional's knowledge re disability and needs</i></p> <p>Sub theme – <i>Lack of health professional's knowledge re disability and needs</i></p> <p>Sub theme – <i>Assistance and support</i></p> <p>Sub theme – <i>Planning and preparation</i></p>
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	<p><i>and basically what I was told was, there is a number on the wall. When I rang I was told we have no classes coming up between now and then so you know, there is nothing really can be done there. So no preparation, nothing as regards labour or anything like that, nothing, I mean all I got was ... the answers to the questions that I asked, like well how will, you know will I be able to do this or will I be, well I was sort of asking will it be painful or you know how will it affect my legs and they didn't seem to, anything I learned throughout the pregnancy I had to go and find for myself, because they didn't seem to know'. (PD7)</i></p> <p><i>'They (antenatal classes) wouldn't be accessible to me because I wouldn't be able to get on mats so I wasn't offered any antenatal classes. I would have liked to have done them if I had the opportunity'. (PD5)</i></p> <p><i>'There was nothing like that (assessment of needs), I found most of the time I was chasing doctors and nurses to ask my own questions, which was awkward'. (PD7)</i></p> <p><i>'He (anaesthetist) looked at my back and went you are not having an epidural and I said why, he said because we don't know where to stick the needle and nobody has done any planning and nobody has done this or that, and we'd have to talk to your neurologist and if you want an epidural it ain't happening today'. (PD8)</i></p> <p><i>'Degrading, it was very degrading, I had to come back here (home) and ask my mum to help me into the bath and so that could be very degrading and I mean and it was, it was quite upsetting for me, because I don't like having to depend on people, I never did depend on people, so it was kind of a new thing for me and I didn't like it to be honest with you, even though I knew it had to be done. I didn't, it wasn't, it often upset me'. (PD7)</i></p> <p><i>'I was just a pregnant woman, just a pregnant woman basically'. (PD5)</i></p>	<p>Sub theme – <i>Planning and preparation</i></p> <p>Sub theme – <i>Planning and preparation</i></p> <p>Sub theme – <i>Planning and preparation</i></p> <p>Theme 4. Impact of experience on woman Sub theme - <i>Dependence</i></p> <p>Sub theme – <i>Sense of normality</i></p>
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<p>Hearing Impaired</p>	<p><i>'I got a letter that said, you need an appointment for a fetal assessment in gynae ward and I said what's that, what's gynae, I never heard that word before, I hadn't heard that word before and you have to agree and I thought, oh dear, I don't know what I'm agreeing to here so I got someone to ring for me and you know, which means again, your privacy is completely compromised, you have to get someone else to ring for you and I said what's this about, you know, and it was to do with my history ... so I wanted them to provide an interpreter and there was a big problem, I said if there's no interpreter available I'm going to bring an interpreter next time and they said, well you've got to pay for the interpreter because we can't cover that'. (H11)</i></p> <p><i>'I had this whole argument, on the phone, I was very upset about it because the manager, of the clinic, the clinic manager was explaining the situation and I said what is the problem now, ... I'm not asking for anything out of the ordinary, ... I want the interpreter ... certified, accredited to do medical work, so then I waited for a long time, and had to go all the way up to the top and eventually they agreed to cover my interpreter, to pay for basically the interpreter that I wanted and who was qualified. But I fought very, very hard'. (H11)</i></p> <p><i>'I realised afterwards when I did bring her (SLI) it was fantastic because there was so much information I never knew, you know, without an interpreter there to, to give you access to everything that they're saying and felt like oh my God and then once I realised all the information that was there, I was able to quiz them, ask them loads of questions ... it was great, really good to have the interpreter there. I was so satisfied ... I was able to have a proper dignified conversation and question and answer session. Whereas before, you know, I was just relying on trying to read their facial expressions and ... also I was able to ask the interpreter things like, what's their voice like, has she got a soft voice or does she, does she sound strict and harsh and the interpreter was</i></p>	<p>Theme 1. Access to services Sub theme - <i>Confidentiality and privacy</i></p> <p>Sub theme - <i>Confidentiality and privacy</i> <i>Choice</i></p> <p>Sub theme - <i>Access to information</i></p>

<p><i>able to explain this to me'. (H11)</i></p> <p><i>'When we're sitting in a waiting room, we have our eyes, you know, on the person coming around and we lip read our own name'. I would remind the person at the reception, desk, my name, because they often forget anyway and they'll call your name, but now when I go in they'll recognise me, now so I'm much more comfortable waiting, but I would never read a magazine, deaf people can never read a magazine in a waiting room like hearing people'. (H11)</i></p> <p><i>'... the woman would do a scan and then they would all talk to each other and I wouldn't know what they were saying'. (H11)</i></p> <p><i>'... didn't have any communication, we were writing notes back and forward but I felt quite shy, my family didn't know about it, it was very hard for me and then I lost the baby, which was worse because I had no access at all to any information for support and the nurse was saying, you'll be fine, you'll be grand, you'll have other babies later on in your life and you'll be alright. That wasn't the point for me, you know, at that time it was about accepting, I just accepted that I was pregnant and then when I lost the baby, my mood just, it hit the floor'. (H11)</i></p> <p><i>'... but for 9 months of the pregnancy I didn't have any interpreter, it was just writing notes back and forth. I mean the doctor did try to tell me what was going on, but, you don't have an interpreter when you're with your GP'. (H11)</i></p> <p><i>'I went in to (maternity unit) and there was like an old fashioned computer and there was an old woman sitting there and I don't like communicating with old, old women, purely because my experience is that their attitude tends to be very old fashioned and</i></p>	<p>Sub theme - <i>Structural environment – antenatal clinic</i></p> <p>Theme 2. Appropriateness of services Sub theme - <i>Interventions – scan</i></p> <p>Theme 3. Responsiveness of services Sub theme – <i>Communication with health professionals</i></p> <p>Sub theme – <i>Communication with health professionals</i></p>
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<p><i>not, you know, something of the past which is very paternalistic so anyway, I sat down, it was my first visit, and she explained to me, she said what's your name, so I wrote down my name. And she wasn't writing anything down and I said, can you write it down and she said no, no, you can lip read me, come on, you can lip read, which immediately then I felt a bit stressed because I hate lip reading, it's a very difficult thing to do and then she started using these words that I didn't understand, or I didn't, I couldn't read from her lips, so then she turned the computer around and I had to look at the screen and it was full of medical words, a screen full of medical words and she said come on, pull your chair around, she said, you know, and have a look at this. I didn't understand what it was'. (H11)</i></p> <p><i>'... my hands were getting swollen and I thought is this the same as my first child, ... I had swollen hands and swollen feet and I thought, well that's okay, I remember my wedding ring that I had, and they wanted me to take it off and it was difficult to take off and, and I started to laugh, you know, I wasn't being serious and the nurse gave out to me for laughing and I didn't know what was going on. And she said we're going to have to cut your ring off and I was saying, oh my God, what's going on, what's wrong'. (H11)</i></p> <p><i>'... they started off talking, you know, away, between each other, and I couldn't hear what they were saying or didn't know what was going on. They were talking to themselves, they weren't communicating with me even by the written word (woman's first language is sign language), they were just, you know, I knew there was something going on but they weren't attempting to communicate with me'. (H11)</i></p> <p><i>'I was nervous as well and when you're nervous it's harder to write English because it's a bit nerve racking anyway because it's not your first language but then under pressure it's worse so then trying to write questions'. I was embarrassed, my confidence fell, ... I felt like they saw me as someone who is very stupid, I'm a confident woman generally but it was so quickly my confidence was totally diminished</i></p>	<p>Sub theme – Exchange of information</p> <p>Sub theme – Communication with health professionals - Disempowering</p> <p>Sub theme – Communication with health professionals Exchange of information</p>
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<p><i>and I, I felt humiliated ... I was starting to panic a little bit ... I felt terrible actually, it did impact me a lot'. (H11)</i></p> <p><i>'I would always love to have the same nurse, I think a lot of deaf people feel like that because it's easier and it was always a different person, it makes it very difficult and of course in a hospital it's always somebody different they change all the time and also quite often they'd be non Irish medical staff and it's just very difficult to lip read people, you know, with strong accents or unfamiliar looking kind of faces, lip reading is very, very difficult, very arduous in the first place, so it makes it that much harder'. (H11)</i></p> <p><i>'I didn't understand it but then I was able to go home and research it on the internet and so on and then I started to understand a little bit more about what is going on. I really needed an interpreter in order to have that basic information'. (H11)</i></p> <p><i>'It was my friends that were really supportive'. (H11)</i></p> <p><i>'I went to see my GP and he asked did I want an interpreter and I said oh yes, I need an interpreter, it's necessary. So he sent a letter out to (maternity unit). I got a letter from (maternity unit) and it said you've requested an interpreter, but, we have a staff nurse here who's able to sign, and then the second one said, the bill for interpreter would be a lot and ... it's too much, you wouldn't be able to have an interpreter and that we have a nurse'. (H11)</i></p> <p><i>'... so I said okay, well who is the interpreter then, because I prefer to get my own interpreter because it's quite a personalised thing and I wanted the same interpreter I had before and the deaf community is very small, ... so anyway, they said the staff nurse was very good and is able to sign and this kind of thing and can interpret, so I</i></p>	<p>Sub theme – <i>Continuity of carer Communication with health professionals Exchange of information</i></p> <p>Sub theme – <i>Sourcing information</i></p> <p>Sub theme – <i>Assistance and support</i></p> <p>Sub theme – <i>Planning and preparation</i></p>
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	<p><i>thought oh okay. So the first visit, I'll be able to check her out and see. She never turned up. She wasn't there. And that worried me'. (H11)</i></p> <p><i>'... there was an antenatal clinic with a group ... and I said I want to know what they're saying because you know, for my first child, I want to know what's going on and so on and I remember them saying you'll be better off with a one to one class, to get information. So I did that and I got the interpreter and so on, and we sat down and watched a video and I remember thinking, oh you're showing me a video, I want human contact, you know, I don't want to just be shown a video, so anyway we watched it and then that was finished, so I wasn't at all satisfied with that, I thought no, that doesn't work, you know'. (H11)</i></p>	<p>Sub theme – <i>Planning and preparation</i></p> <p>Sub- theme – <i>Planning and preparation</i></p>
<p>Vision Impaired</p>	<p><i>'... I asked my husband to buy a pregnancy test. I couldn't do a pregnancy test on my own ... I had to ask my husband to read it for me'. (V18)</i></p> <p><i>'It (maternity unit) was easy enough to get to and it was easy to get to from work. So I just got a taxi and I could find my way there myself and that was really useful and really important for me'. (V18)</i></p> <p><i>'... big room that's good but for a blind person that's really hard, it's like take a seat, where, all I can hear is this big massive room and I have no idea where the seats were'. (V18)</i></p> <p><i>'... my husband was with me ... the obstetrician actually had become really quite aware so that was the only time and he actually guided me to the seat which was great'. (V18)</i></p> <p><i>'We went to my GP and my GP said have you thought about delivery and I said how about a homebirth and she didn't think it was safe. And I was quite disappointed and</i></p>	<p>Theme 1. Access to services Sub theme – <i>Barriers to diagnosis of pregnancy</i> Sub theme – <i>Structural environment – transport</i></p> <p>Sub theme – <i>Structural environment – antenatal clinic</i></p> <p>Sub theme – <i>Structural environment – navigating the clinic</i></p> <p>Sub theme – <i>Choice</i></p>

<p><i>'At the initial meeting she (GP) handed me a booklet and they were obviously in an inaccessible format so I had to get my husband to read them for me'. (VI8)</i></p> <p><i>'There was nothing in any other format. The only thing I ever got in any other format was caring for your baby from birth to 6 months, or birth to 6 weeks and it was from the public health nurse after the baby was born and it had a CD in the back of it but the CD was like oh refer to the diagram in the book, it wasn't designed for blind people, it was designed for ease of access for other people. It's frustrating and it undermines you and it highlights the difficulties, that your different and you know I'm very lucky that I have that kind of a relationship with my husband and that my husband is sighted'. (VI8)</i></p> <p><i>'... didn't have access to books or anything like that that other people had, I kind of just looked up the internet'. (VI8)</i></p> <p><i>'... an Australian website, it's midwifery website by, it's like an on line antenatal class and it was very, very good, I found that really, really helpful because it gave me the information that I wanted and it went through all sorts of things like abnormalities and stuff ... it's good to have access to the information'. (VI8)</i></p> <p><i>'... the scan showed that everything was fine and everything was normal but I kind of felt that I was kind of shoehorned into the service and I don't think it was necessarily the most appropriate service. I think that I would probably have got on a lot better with a midwife and I think that a midwife, this might be my assumptions but I think the midwife would probably have more of a holistic approach, would probably have more of a human approach to an obstetrician and the midwife is experienced or an expert in normal pregnancy whereas an obstetrician is kind of more expert in problems and I didn't want to go down the problem route'. (VI8)</i></p> <p><i>'scans ... I couldn't see any of those. I had to ask to hear the heart beat ... that was</i></p>	<p>Theme 2. Appropriateness of services Sub theme – <i>Exchange of information</i></p> <p>Sub theme – <i>Exchange of information</i></p> <p>Sub theme – <i>Sourcing information</i></p> <p>Sub theme – <i>Sourcing information</i></p> <p>Sub theme – <i>Interventions</i></p> <p>Sub theme –</p>
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<p><i>very, very exciting, it was a big strong heart beat'.(VI8)</i></p> <p><i>'When we went for ... the big scan, yeah that was good, she (midwife) was very good actually, she really explained what was on the screen'. (VI8)</i></p> <p><i>'... my GP would be aware that it's important for her to say where she is and tell me where to sit exactly and those kind of things because in a none familiar environment I wouldn't be aware. And for me building a rapport with somebody is really important for me you need to know what they're going to do before they do it. So if there's suddenly this hand or this wet thing or this cold thing or whatever on you, it's very disconcerting'. (VI8)</i></p> <p><i>'I didn't want to go through the whole big medical, medical thing and so I had made an appointment with an obstetrician and she obviously had the referral letter, God only knows what the GP put in the referral letter because the obstetrician then refused to see me. I asked her why and she said oh she doesn't think it would work out, actually don't think it will work out with her and I couldn't understand why that was happening, it didn't make sense to me and I was a bit upset about it'. (VI8)</i></p> <p><i>'I found him (obstetrician) excellent. Going to see the same person all the time is really, really important, they can get to know me because my experience is that people tend to be a little bit, not patronizing, if they don't know, don't have an experience of blind people, they might not feel comfortable, they might not know, they might trip over their words or they might, just not feel comfortable and just not treat me in a normal way. And that's been my experience of doctors in particular. And so it was really sensible to go have the same person all the time'. (VI8)</i></p> <p><i>'... practically all of them asked me about my sight ... how much can you see and all that kind of stuff, ... and then they asked me about the condition. Then it was like well the child, will that have the same sight and we said it's a 50/50 chance and one person</i></p>	<p><i>Interventions</i></p> <p>Theme 3. Responsiveness of services Sub theme – <i>Interaction with health professionals</i></p> <p>Sub theme – <i>Interaction with health professionals</i> <i>Lack of health professionals knowledge about disability</i></p> <p>Sub theme – <i>Interaction with health professionals – continuity of carer</i></p> <p>Sub theme – <i>Disability took precedence – emphasis on screening</i></p>
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<p><i>asked me would I like to be tested, another person asked me would I consider pre implantation screening. Pre implantation screening, warning bells going off in my head, is that legal'. (VI8)</i></p> <p><i>' I got really, really upset and really insulted by that, it suggests that being blind is something so horrific and so horrible that you'd be willing to abort a child which was one of the things that we sort of, screening and potentially aborting or pre implantation screening, that I would put myself through so much to avoid passing on one of my characteristics. I felt really, really upsetting. Its abnormal in my family to be able to see'. (VI8)</i></p> <p><i>'Screening ... the suggestion that you would do anything to avoid passing on these genes and its passing on part of me which is such a disrespect to a part of me that I'm not, proud of is a different, a feeling of being proud of it, it's who I am, it's what I am and I don't want to be different, I don't want to be cured, I don't want to be changed, I'm happy with the way I am and I think I'm ok the way I am. And I think that it would be ok for a child to inherit parts of me, like it would be ok for them to inherit parts of their father or whatever'. (VI8)</i></p> <p><i>'I'll keep my fingers crossed that your child doesn't have inherited the condition, which is fine and of course you hope that the child doesn't have the condition in some ways but again there was that slight kind of inference that it's not normal'. (VI8)</i></p> <p><i>'... my GP asked me how I was going to feed the baby and I said well breast feed and she said do you think you'll be able to manage that because you know it's quite a difficult thing to do and I thought that was a really strange thing to ask. I was kind of thinking why would it be any more difficult for me to breast feed than anybody else, surely it's a kind of a touch thing, you can feel it and ... actually I felt that it would be much more difficult to make the bottle formula than it would be to breast feed because I wouldn't be able to know water, be able to measure the spoon of formula'. (VI8)</i></p>	<p>Sub theme – <i>Disability took precedence – emphasis on screening</i></p> <p>Sub theme – <i>Interaction with health professionals – Attitudes</i></p>
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	<p><i>'It's just subtle attitudes from people like you hear people saying this pregnant woman with a guide dog, there's almost kind of horror and it kind of makes you feel kind of grotesque and not quite human because they're just thick you know and when I was pregnant it was very much like how, you know that's dreadful, that was kind of the impression'. (VI8)</i></p> <p><i>'So we booked a 1 day thing with (name) ... a one to one session ... that worked out quite well'. (VI8)</i></p>	<p>Sub theme – <i>Interaction with health professionals – Attitudes</i></p> <p>Sub theme – <i>Planning and preparation</i></p>
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6b Data Analysis (Second round coding – Analytical Coding)

Coding Frame

This coding frame was used in the second round of coding for each transcript. Once the first round (literal coding) was completed, the data excerpts were inserted into the frame under the most appropriate broad theme and subtheme. Once inserted, the data were reviewed for appropriateness to that broad theme and subtheme. It was then recoded and re-categorised if necessary. The subthemes were extended to capture the essence of the woman’s experiences.

Broad Theme	Theme 1. Availability	Theme 2. Accessibility	Theme 3. Accommodation	Theme 4. Affordability	Theme 5. Acceptability
Definition	The relationship between the extent and type of services available to address women’s needs	The relationship between the location of the women and the location of the services	The relationship between the service providers and the organisation of resources to accommodate women	Refers to the women’s ability to afford the services	Refers to the relationship established between health services providers and the women
Structural environment					
Lack of health professional’s knowledge of services					
Informed consent					
Choice					
Confidentiality					

and Privacy					
Barriers to diagnosis (disability specific)					
Interventions (Scan)					
Assessment of MH status/assessment tools					
Person-centredness					
Communication with health professionals					
Exchange of information					
Sourcing information					
Inter-professional collaboration (referrals, e.g. alternative therapies)					
Continuity of care/carer					
Planning and preparation					

(assessment of needs/birth plan/antenatal classes)					
Sensitivity					
Assistance and support					
Parenting (role and skills)					
Lack of health professional's knowledge re disability and needs					
Interactions with health professionals (attitudes)					
Normality					
Flexibility of policies and procedures					

6c Data Analysis (Second round coding – Analytical Coding)

Pregnancy

Disability Strand	Text/Quote	Themes and subthemes [Analytical Coding]
<p>Physical Disability</p>	<p><i>'My local GP was actually treating me for gastro-enteritis and didn't think to ask you know was I pregnant or you know look for a urine sample or anything like that. It was only myself, it kind of registered with me, I thought to myself well gastro-enteritis can't last for 3 weeks, 3 or 4 weeks, so it was just by accident I kind of went in and said to myself well I'll take the pregnancy test and I'll see what happens and it came out positive then'. (P7)</i></p> <p><i>'Transport was a difficult thing, getting taxis to go into town early in the morning is very difficult, not a lot of them will go in because a) they will get caught in traffic and b) they won't get a run to bring them out again. So not a lot of them will go in'. 'Buses ... were quite difficult, with schedules and things, I often missed appointments, early appointments due to traffic and different things like that'. (P7)</i></p> <p><i>'Yeah transport was the main problem, appointments were always made very earlier and it was difficult to kind of arrange some other time and when I didn't, I was kind of confronted with phone calls saying well you know why haven't you turned up and you know what is going on here and you've missed this appointment again, you know we can't keep re-scheduling, that was the kind of attitude now no matter how many times you try and tell them look it is difficult to get in, you kind of met with a blank wall'. (P7)</i></p>	<p>Theme 2 [T2] Accessibility T2 Barriers to diagnosing pregnancy</p> <p>T2 Structural environment- transport</p> <p>T2 Difficulty making appointment</p>

	<p><i>'Late at night I actually had to go in to have an emergency scan (woman had a bleed), but me not thinking and this being my first pregnancy, I went to the first hospital that was nearest, I went into (general hospital) and a nurse there actually, for want of a better word gave out to me, you know saying well this isn't a maternity hospital and you should have went to (maternity unit)'. (P7)</i></p> <p><i>'Basically getting it from the internet or, I asked, my mum has a friend and she has CP and she had a baby, she had 4 kids now, so I kind of sat with her and asked her a few things'. (PD7)</i></p> <p><i>'I was saying to him (doctor in maternity unit) ... can you explain that to me please, what are you talking about, I'll discuss it with you in a minute was the kind of and very sharp you know, kind of no I'm doing something and me you know worrying there is something seriously wrong (with baby), but the attitude I was confronted with was well I'm doing something, I'll get around to you when I'm ready to get around to you'. 'He was the only negative one I came across, that was fairly, you know my opinion is my opinion and I don't have to discuss it with you, if I don't want to, you know that kind of way'. (P7)</i></p> <p><i>'He (GP) seemed kind of arrogant ... I had asked him to come up to the house because I couldn't move, I was really, really sick and he seemed to be well you know my dinner is on the table and that kind of attitude and I have to go home, I have had a surgery of patients all day'. (P7)</i></p> <p><i>'I have to say ... the midwives were very good and they were very helpful.</i></p>	<p>Theme 1 [T1] Availability T1 Structure of publicly-funded health services</p> <p>Theme 3 [T3] Accommodation T3 Scouring information</p> <p>Theme 5 [T5] Acceptability T5 Interpersonal and interactions with health professionals - attitudes</p> <p>T5 Interpersonal and interactions with health professionals - attitudes</p> <p>T5 Interpersonal and interactions with health</p>
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	<p><i>Yeah, they were quite helpful, I mean any questions I had as in regards to what was going to happen or pain wise or anything like that, they were always very open and very upfront, you know and very co-operative and very helpful, so there was no problem there with them, there was just the one, but you always get the kind of the one that will make things difficult for you'. (P7)</i></p> <p><i>'Basically(H.P. name) said to us I help loads of disabled women to get pregnant but they've all had accidents which made them disabled, none of them had genetic impairments, so basically he was saying that if there was any risk, we couldn't guarantee that we wouldn't have a disabled child, he didn't want to know, that was pretty much it. Thankfully I'm a very stubborn person and I refused to let their prejudice impact on my life and also thankfully I have met some amazing people over the years'. (P5)</i></p> <p><i>'He (doctor in maternity unit) didn't really tell me anything ... he was kind of another one rushing me up for scans this, that and the other'. (P7)</i></p> <p><i>'You are trying to grab these people and say well look and ask these kind of questions, well what is going to happen or you know what is going to be done or what are you doing to me or you know that kind of way. And it is quite frightening, especially when you can't get the time with them to say well listen this is the way I want things to go or this is more comfortable for me and when you are being met with a blank wall, as in regards to that it is scary, it is quite scary'. (PD7)</i></p> <p><i>'In the hospital I wasn't believed, I wasn't listened to'. (P8)</i></p>	<p><i>professionals – support and assistance</i></p> <p><i>T5 Interpersonal and interactions with health professionals - attitudes</i></p> <p><i>T3 Exchange of information</i></p> <p><i>T3 Exchange of information</i></p> <p><i>T5 Interpersonal relationships and interactions with health professionals</i></p>
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	<p><i>'They (H.Ps) talked over me an awful lot of the time and even, no matter how many times you said hello you know I'm here, yeah I'm in the room, you know talking over me, it was still kind of very well, you know this has to be done with her and that has to be done with her, so it wasn't, it was very closed off'. (P7)</i></p> <p><i>'They (doctors maternity unit) kept saying to me, well we've had people that can't feel from below the waist and she kept referring to this not feeling from below the waist and no matter how many times I tried to tell her, she still referred back to, oh we have had many people that can't feel from the waist down. It was kind of like, yeah well you are telling us this but we are going to try this. They didn't seem to know ... much about my condition, if anything. It was kind of like they (H.P.s) were generalising'. (P7)</i></p> <p><i>'I had to tell them (about the disability). I think in a way it's better because if they already have ideas they might have preconceptions that are not correct, so I think it was in a way better because it meant that I was the expert'. (P5)</i></p> <p><i>'The physiotherapist had said, I was asking her questions, how will it affect the legs and the back and this that and the other and her answer to me was kind of like well I know as much about it as you do'. (PD7)</i></p> <p><i>'My partner would have been there most of the time, so he would have been the main source of help there'. (P5)</i></p> <p><i>'I was only referred to an ante-natal class towards the end, I mean in the last 2 weeks of the pregnancy which is absolute lunacy. I had enquired about it myself before hand anbasically what I was told was, there is a</i></p>	<p><i>T5 Interpersonal relationships and interactions with health professionals</i></p> <p><i>T5 Lack of knowledge</i></p> <p><i>T5 Health professional's lack of knowledge</i></p> <p><i>T5 Health professional's lack of knowledge</i></p> <p><i>T5 Support and assistance</i></p> <p><i>T3 Planning and preparation</i></p>
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	<p><i>number on the wall. When I rang I was told we have no classes coming up between now and then so you know, there is nothing really can be done there. So no preparation, nothing as regards labour or anything like that, nothing, I mean all I got was ... the answers to the questions that I asked, like well how will, you know will I be able to do this or will I be, well I was sort of asking will it be painful or you know how will it affect my legs and they didn't seem to, anything I learned throughout the pregnancy I had to go and find for myself, because they didn't seem to know'. (D7)</i></p> <p><i>'They (antenatal classes) wouldn't be accessible to me because I wouldn't be able to get on mats so I wasn't offered any antenatal classes. I would have liked to have done them if I had the opportunity'. (P5)</i></p> <p><i>'There was nothing like that (assessment of needs), I found most of the time I was chasing doctors and nurses to ask my own questions, which was awkward'. (P7)</i></p> <p><i>'He (anaesthetist) looked at my back and went you are not having an epidural and I said why, he said because we don't know where to stick the needle and nobody has done any planning and nobody has done this or that, and we'd have to talk to your neurologist and if you want an epidural it ain't happening today'. (P8)</i></p> <p><i>'I was just a pregnant woman, just a pregnant woman basically'. (P5)</i></p>	<p><i>T3 Planning and preparation- antenatal classes</i></p> <p><i>T3 Planning and preparation -assessment of needs</i></p> <p><i>T3 Planning and preparation</i></p> <p><i>T5 Normality</i></p>
<p>Hearing Impaired</p>	<p><i>'I got a letter that said, you need an appointment for a fetal assessment in gynae ward and I said what's that, what's gynae, I never heard that word before, I hadn't heard that word before and you have to agree and I thought, oh dear, I don't know what I'm agreeing to here so I got someone to ring for me and you know, which means again, your privacy is</i></p>	<p><i>T2 Confidentiality and privacy</i></p>

	<p><i>completely compromised, you have to get someone else to ring for you and I said what's this about, you know, and it was to do with my history ... so I wanted them to provide an interpreter and there was a big problem, I said if there's no interpreter available I'm going to bring an interpreter next time and they said, well you've got to pay for the interpreter because we can't cover that'. (H1)</i></p> <p><i>'I had this whole argument, on the phone, I was very upset about it because the manager, of the clinic, the clinic manager was explaining the situation and I said what is the problem now, ... I'm not asking for anything out of the ordinary, ... I want the interpreter ... certified, accredited to do medical work, so then I waited for a long time, and had to go all the way up to the top and eventually they agreed to cover my interpreter, to pay for basically the interpreter that I wanted and who was qualified. But I fought very, very hard'. (H1)</i></p> <p><i>'I realised afterwards when I did bring her (SLI) it was fantastic because there was so much information I never knew, you know, without an interpreter there to, to give you access to everything that they're saying and felt like oh my God and then once I realised all the information that was there, I was able to quiz them, ask them loads of questions ... it was great, really good to have the interpreter there. I was so satisfied ... I was able to have a proper dignified conversation and question and answer session. Whereas before, you know, I was just relying on trying to read their facial expressions and ... also I was able to ask the interpreter things like, what's their voice like, has she got a soft voice or does she, does she sound strict and harsh and the interpreter was able to explain this to me'. (H1)</i></p> <p><i>'When we're sitting in a waiting room, we have our eyes, you know, on the</i></p>	<p><i>T3 Communicating with health professionals</i></p> <p><i>T3 Communicating with health professionals</i></p> <p><i>T3 Structural environment – antenatal clinic</i></p>
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	<p><i>person coming around and we lip read our own name'. I would remind the person at the reception, desk, my name, because they often forget anyway and they'll call your name, but now when I go in they'll recognise me, now so I'm much more comfortable waiting, but I would never read a magazine, deaf people can never read a magazine in a waiting room like hearing people'. (H1)</i></p> <p><i>'... the woman would do a scan and then they would all talk to each other and I wouldn't know what they were saying'. (H1)</i></p> <p><i>'... didn't have any communication, we were writing notes back and forward but I felt quite shy, my family didn't know about it, it was very hard for me and then I lost the baby, which was worse because I had no access at all to any information for support and the nurse was saying, you'll be fine, you'll be grand, you'll have other babies later on in your life and you'll be alright. That wasn't the point for me, you know, at that time it was about accepting, I just accepted that I was pregnant and then when I lost the baby, my mood just, it hit the floor'. (H1)</i></p> <p><i>'... but for 9 months of the pregnancy I didn't have any interpreter, it was just writing notes back and forth. I mean the doctor did try to tell me what was going on, but, you don't have an interpreter when you're with your GP'. (H1)</i></p> <p><i>'I went in to (maternity unit) and there was like an old fashioned computer and there was an old woman sitting there and I don't like communicating with old, old women, purely because my experience is that their attitude tends to be very old fashioned and not, you know, something of the past which is very paternalistic so anyway, ...and she wasn't writing anything</i></p>	<p><i>T3 Communicating with health professionals</i></p> <p><i>T3 Communicating with health professionals</i></p> <p><i>T3 Communicating with health professionals</i></p> <p><i>T5 Interpersonal relationship and interactions with health professionals - attitudes</i></p>
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	<p><i>down and I said, can you write it down and she said no, no, you can lip read me, come on, you can lip read, which immediately then I felt a bit stressed because I hate lip reading, it's a very difficult thing to do and then she started using these words that I didn't understand'. (H1)</i></p> <p><i>'... my hands were getting swollen and I thought is this the same as my first child, ... I had swollen hands and swollen feet and I thought, well that's okay, I remember my wedding ring that I had, and they wanted me to take it off and it was difficult to take off and, and I started to laugh, you know, I wasn't being serious and the nurse gave out to me for laughing and I didn't know what was going on. And she said we're going to have to cut your ring off and I was saying, oh my God, what's going on, what's wrong'. (H1)</i></p> <p><i>'... they started off talking, you know, away, between each other, and I couldn't hear what they were saying or didn't know what was going on. They were talking to themselves, they weren't communicating with me even by the written word (woman's first language is sign language), they were just, you know, I knew there was something going on but they weren't attempting to communicate with me'. (H1)</i></p> <p><i>'I was nervous as well and when you're nervous it's harder to write English because it's a bit nerve racking anyway because it's not your first language but then under pressure it's worse so then trying to write questions'. I was embarrassed, my confidence fell, ... I felt like they saw me as someone who is very stupid, I'm a confident woman generally but it was so quickly my confidence was totally diminished and I, I felt humiliated ... I was starting to panic a little bit ... I felt terrible actually, it did impact me a lot'. (H1)</i></p> <p><i>'I would always love to have the same nurse, I think a lot of deaf people</i></p>	<p><i>T3 Exchange of information</i></p> <p><i>T3 Communicating with health professionals</i></p> <p><i>T3 Communicating with health professionals</i></p>
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	<p><i>feel like that because it's easier and it was always a different person, it makes it very difficult'. (H1)</i></p> <p><i>'[N]on Irish medical staff and it's just very difficult to lip read people, you know, with strong accents or unfamiliar looking kind of faces, lip reading is very, very difficult, very arduous in the first place, so it makes it that much harder'. (H1)</i></p> <p><i>'I didn't understand it but then I was able to go home and research it on the internet and so on and then I started to understand a little bit more about what is going on. I really needed an interpreter in order to have that basic information'. (H1)</i></p> <p><i>'I went to see my GP and he asked did I want an interpreter and I said oh yes, I need an interpreter, it's necessary. So he sent a letter out to (maternity unit). I got a letter from (maternity unit) and it said you've requested an interpreter, but, we have a staff nurse here who's able to sign, and then the second one said, the bill for interpreter would be a lot and ... it's too much, you wouldn't be able to have an interpreter and that we have a nurse'. (H1)</i></p>	<p>T3 Continuity of carer</p> <p>T3 Communicating with health professionals</p> <p>T3 Sourcing information</p> <p>T3 Communicating with health professionals</p>
<p>Vision Impaired</p>	<p><i>'... I asked my husband to buy a pregnancy test. I couldn't do a pregnancy test on my own ... I had to ask my husband to read it for me'. (V8)</i></p> <p><i>'It (maternity unit) was easy enough to get to and it was easy to get to from work. So I just got a taxi and I could find my way there myself and that was really useful and really important for me'. (V8)</i></p> <p><i>'... big room that's good but for a blind person that's really hard, it's like</i></p>	<p>T2 Barriers to diagnosing pregnancy</p> <p>T2 Structural environment – transport</p> <p>T2 Structural environment – navigating the</p>

	<p><i>take a seat, where, all I can hear is this big massive room and I have no idea where the seats were'. (V8)</i></p> <p><i>'We went to my GP and my GP said have you thought about delivery and I said how about a homebirth and she didn't think it was safe. And I was quite disappointed and then I said I would prefer to have a kind of a midwife led service rather than a medical kind of service, or rather than a doctor, an obstetrician type service ... then said we fell out of the catchment area for a midwife service, led service so that wasn't an option'. (V8)</i></p> <p><i>'I liked the home birth idea, the reason why I wanted a home birth was because I didn't want to go to a big hospital because people come in and out, especially it was a big ward, could have been the Nightingale ward for all I knew, people coming in and out, you can't actually relax because you haven't, don't know who anyone is, you feel very, very vulnerable as a blind person, it could be anyone coming in and you can't see if someone is wearing a uniform or not or see their ID cards or anything like that, they could be taking my baby or they could be doing whatever and that's a very, very, it's a very stressful, very, very stressful environment for a blind person'. (V8)</i></p> <p><i>'... my GP said that if I went down the route of getting an independent midwife she would have nothing more to do with it [pregnancy]'. (V8)</i></p> <p><i>'At the initial meeting she (GP) handed me a booklet and they were obviously in an inaccessible format so I had to get my husband to read them for me'. (V8)</i></p> <p><i>'There was nothing in any other format. The only thing I ever got in any other format was caring for your baby from birth to 6 months, or birth to 6</i></p>	<p><i>clinic</i></p> <p>T1 Choice</p> <p>T1 Choice</p> <p>T1 Choice</p> <p>T3 Exchange or information</p> <p>T3 Exchange of information</p>
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	<p><i>weeks and it was from the public health nurse after the baby was born and it had a CD in the back of it but the CD was like oh refer to the diagram in the book, it wasn't designed for blind people, it was designed for ease of access for other people. It's frustrating and it undermines you and it highlights the difficulties, that your different and you know I'm very lucky that I have that kind of a relationship with my husband and that my husband is sighted'. (V8)</i></p> <p><i>'... didn't have access to books or anything like that that other people had, I kind of just looked up the internet'. (V8)</i></p> <p><i>'... an Australian website, it's midwiferywebsite'. (V8)</i></p> <p><i>'... I kind of felt that I was kind of shoehorned into the service and I don't think it was necessarily the most appropriate service. I think that I would probably have got on a lot better with a midwife and I think that a midwife, this might be my assumptions but I think the midwife would probably have more of a holistic approach, would probably have more of a human approach to an obstetrician and the midwife is experienced or an expert in normal pregnancy whereas an obstetrician is kind of more expert in problems and I didn't want to go down the problem route'. (V8)</i></p> <p><i>'scans ... I couldn't see any of those. I had to ask to hear the heart beat ... that was very, very exciting, it was a big strong heart beat'. (V8)</i></p> <p><i>'When we went for ... the big scan, yeah that was good, she (midwife) was very good actually, she really explained what was on the screen'. (V8)</i></p> <p><i>'... my GP would be aware that it's important for her to say where she is and tell me where to sit exactly and those kind of things because in a none</i></p>	<p><i>T3 Sourcing information</i></p> <p><i>T3 Sourcing information</i></p> <p><i>T1 Choice</i></p> <p><i>T3 Exchange of information</i></p> <p><i>T3 Exchange of information</i></p> <p><i>T5 Interpersonal relationship and interactions</i></p>
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	<p><i>familiar environment I wouldn't be aware. And for me building a rapport with somebody is really important for me you need to know what they're going to do before they do it. So if there's suddenly this hand or this wet thing or this cold thing or whatever on you, it's very disconcerting'. (V8)</i></p> <p><i>'I didn't want to go through the whole big medical, medical thing and so I had made an appointment with an obstetrician and she obviously had the referral letter, God only knows what the GP put in the referral letter because the obstetrician then refused to see me. I asked her why and she said oh she doesn't think it would work out, ...that didn't make sense to me and I was a bit upset about it'. (V8)</i></p> <p><i>'I found him (obstetricians) excellent. Going to see the same person all the time is really, really important, they can get to know me because my experience is that people tend to be a little bit, not patronizing, if they don't know, don't have an experience of blind people, they might not feel comfortable, they might not know, they might trip over their words or they might, just not feel comfortable and just not treat me in a normal way. And that's been my experience of doctors in particular. And so it was really sensible to go have the same person all the time'. (V8)</i></p> <p><i>'... practically all of them asked me about my sight ... how much can you see and all that kind of stuff, ... and then they asked me about the condition. Then it was like well the child, will that have the same sight and we said it's a 50/50 chance and one person asked me would I like to be tested, another person asked me would I consider pre implantation screening. Pre implantation screening, warning bells going off in my head, is that legal'. (V8)</i></p> <p><i>' I got really, really upset and really insulted by that, it suggests that being</i></p>	<p><i>with health professionals</i></p> <p><i>T5 Interpersonal relationship and interactions with health professionals</i></p> <p><i>T5 Interpersonal relationship and interactions with health professionals</i></p> <p><i>T5 Health professional's lack of knowledge</i></p> <p><i>T5 Screening for inherited conditions</i></p>
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	<p><i>blind is something so horrific and so horrible that you'd be willing to abort a child which was one of the things that we sort of, screening and potentially aborting or pre implantation screening, that I would put myself through so much to avoid passing on one of my characteristics. I felt really, really upsetting. Its abnormal in my family to be able to see'. (V8)</i></p> <p><i>'Screening ... the suggestion that you would do anything to avoid passing on these genes and its passing on part of me which is such a disrespect to a part of me that I'm not, proud of is a different, a feeling of being proud of it, it's who I am, it's what I am and I don't want to be different, I don't want to be cured, I don't want to be changed, I'm happy with the way I am and I think I'm ok the way I am. And I think that it would be ok for a child to inherit parts of me, like it would be ok for them to inherit parts of their father or whatever'. (V8)</i></p> <p><i>'I'll keep my fingers crossed that your child doesn't have inherited the condition, which is fine and of course you hope that the child doesn't have the condition in some ways but again there was that slight kind of inference that it's not normal'. (V8)</i></p> <p><i>'It's just subtle attitudes from people like you hear people saying this pregnant woman with a guide dog, there's almost kind of horror and it kind of makes you feel kind of grotesque and not quite human because they're just thick you know and when I was pregnant it was very much like how, you know that's dreadful, that was kind of the impression'. (V8)</i></p> <p><i>'So we booked a 1 day thing with (name) ... a one to one session ... that worked out quite well'. (V8)</i></p>	<p><i>T5 Screening for inherited conditions</i></p> <p><i>T5 Screening for inherited conditions</i></p> <p><i>T5 Perceptions of disability</i></p> <p><i>T5 Interpersonal relationship and interactions with health professionals</i></p> <p><i>T3 Planning and preparation – antenatal classes</i></p>
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Appendix 7 Participant demographic figures – interviews with women

Figure 4 Physical disability – underlying cause of disability

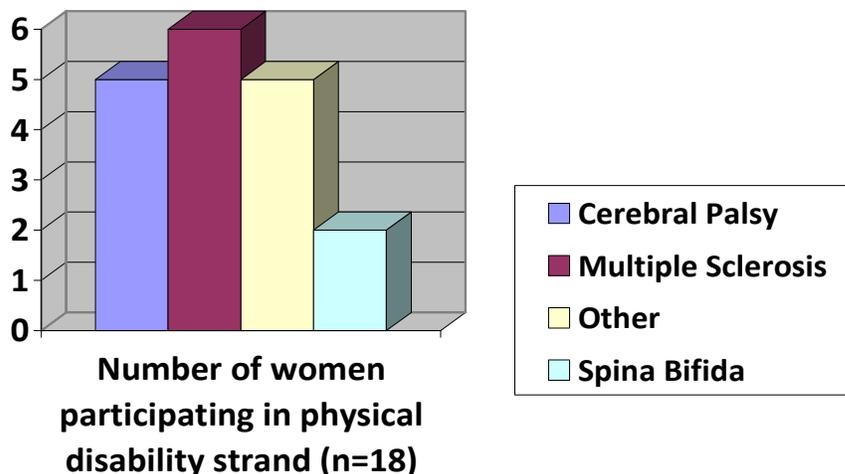


Figure 5 Physical disability - age profile of women

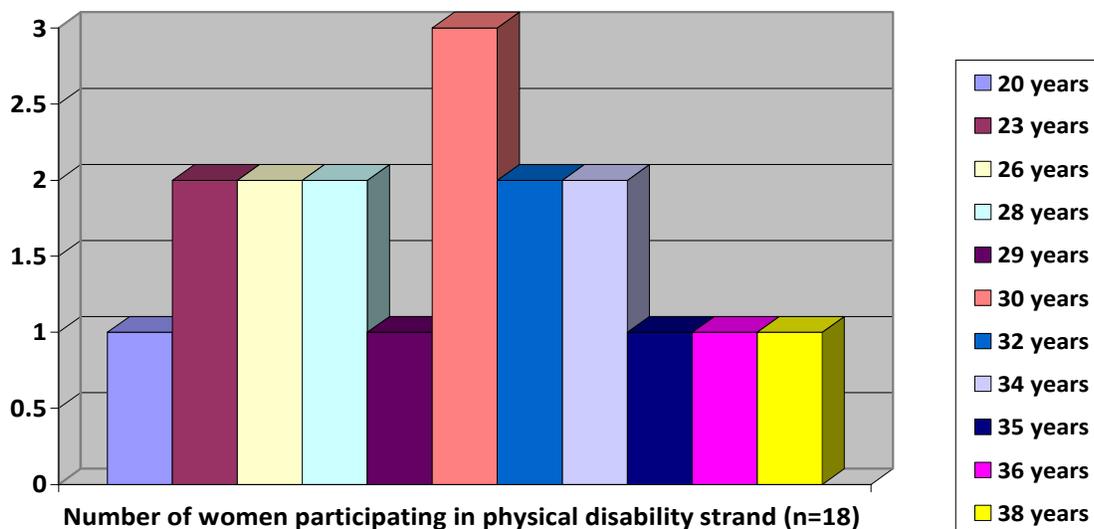


Figure 6 Hearing impairment - age profile of women

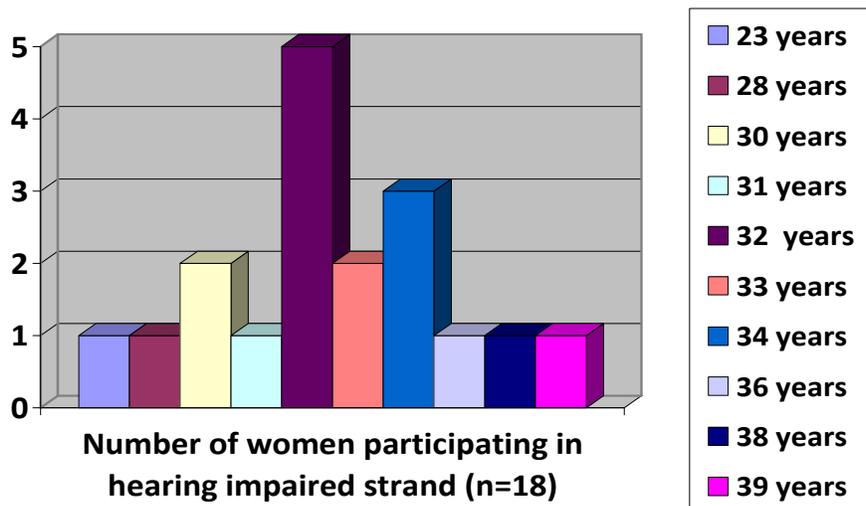


Figure 7 Vision impairment - age profile of women

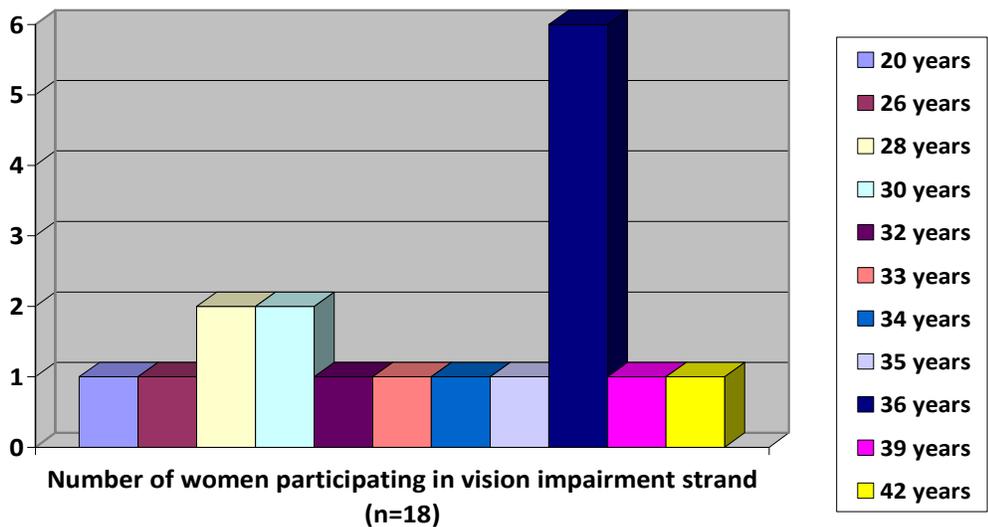


Figure 8 Mental health – age profile of women

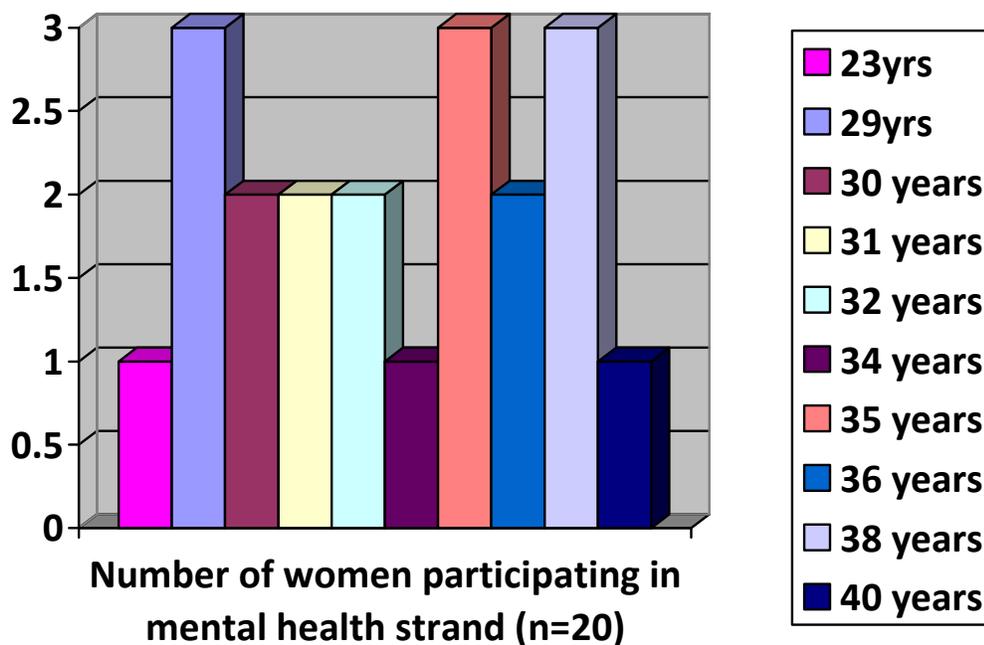


Figure 9 Intellectual disability - age profile of women

