

Equality Commission

FOR NORTHERN IRELAND

Disabled Women in Northern Ireland: Situation, Experiences and Identity



The European Year of People with Disabilities

**Equality Commission
for Northern Ireland**

**Disabled Women
in Northern Ireland:
Situation, Experiences and Identity**

Re-thinking Identity.....

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Note: Throughout this document we have used the term 'disabled people' to reflect the Commission's belief in the social model of disability (ie that it is the barriers that society puts in place, rather than the nature and severity of any impairment, that truly dis-able people). However, we appreciate that this might not be the preferred term of some readers.

Contents	Page
Background	1
Key Findings	2
Social Profile of Disabled Women in Northern Ireland	3
Literature Review	6
Focus Group Report	15
Conclusions & Recommendations	31
References	33

Background

The Equality Commission is a member of the Joint Equality and Human Rights Forum alongside the Northern Ireland Human Rights Commission, the Equality Authority and the Human Rights Commission (Republic of Ireland), the Equal Opportunities Commission, the Commission for Racial Equality and the Disability Rights Commission (Great Britain).

As one of its first co-operative ventures, the Forum commissioned a joint research project to explore the reality of diversity in people's identity. Each member undertook a separate piece of research following a common approach. Other members worked on : black and minority ethnic women in Britain (EOC), black and minority ethnic people with disabilities in Ireland (EA), young gay, lesbian and bisexual people in Northern Ireland (NIHRC), young minority ethnic men in Great Britain (CRE), and lesbian, gay and bisexual disabled people in Great Britain (DRC).

The Commission conducted research on the situation, experience and identity of disabled women. The primary aim of the research was to sketch a profile of the multiple identity group, disabled women; in simple terms, to answer the question 'How do people in this group define themselves?' The focus is to consider how people understand and perceive their identity.

The research included:

- An examination of existing quantitative datasets in order to paint a profile of disabled women in Northern Ireland

- A literature review of recent research on disabled women in relation to equality and/or human rights issues

- Focus group discussions with disabled women and representatives of the health sector

Key Findings

Disabled women were less likely to be in paid employment compared to disabled men and women who were not disabled.

Disabled women were more likely to participate in higher education than disabled men.

Disabled people overall were more likely to have experienced a lot or a great deal of stress or worry than people who were not disabled.

There is evidence within the literature which shows that disabled women experience double oppression.

Disabled women have been denied the opportunity to form relationships and/or have children.

Disabled women experience feelings of rolelessness as not expected to have a career or assume the caring roles other women experience.

Disabled women do require and provide care and support for others.

Disabled women reported that they receive inadequate levels of support from statutory bodies. That necessary support is often found among other disabled people, particularly other disabled women.

Social Profile of Disabled Women in Northern Ireland

In the absence of an up to date survey of the nature and extent of disability, key facts on disabled women in Northern Ireland have been drawn from a number of sources relating to labour market participation, higher and further education participation and a health and well being profile. Awareness of the Disability Discrimination Act, 1995, (the DDA) was examined as well as experiences of service provision through research conducted by the Equality Commission.

It should be noted that all of the surveys quoted below use different definitions of disability and are therefore not comparable. The definitions used in the Labour Force Survey and the Health and Well Being Survey are comparable to that of the DDA. Information on disability used in the further and higher education statistics is collected at individual colleges and therefore may not be consistent with the definition used in the legislation. In addition it should also be noted that small sample sizes have limited the extent of the analysis of the respective surveys.

Labour Market Participation

Analysis of the Labour Force Survey (autumn 2001) shows that just under one fifth of people of working age in Northern Ireland are disabled. Of those in employment only 10% are disabled. Disabled women (45%) were more likely than disabled men (42%) and women who are not disabled (21%) to have no formal qualifications. Disabled women (30%) were less likely to be in employment than disabled men (41%) and women who are not disabled (68%). In contrast disabled women (69%) are much more likely to be economically inactive than women who are not disabled (28%).

	Disabled		Not disabled	
	Women %	Men %	Women %	Men %
No formal qualifications	45	42	21	20
In employment	30	41	68	82
Economically inactive	69	54	28	12

Source Labour Force Survey Autumn 2001

Higher Education Participation

Data collected by the Higher Education Statistics Agency show that 5% of all students enrolled to study full time in higher education institutions in Northern Ireland during the academic year 2001-2002 were disabled. Disabled women (55%) showed higher participation rates than disabled men (45%) and lower than women who are not disabled (60%). Disabled women (12%) were more likely to enrol for higher education courses than women who were not disabled (8%).

Disabled women were studying a wide range of subjects but were less likely to study subjects related to engineering, architecture and agriculture than disabled men. In contrast, disabled women were more likely to study subjects related to medicine, biological sciences and social, economic and political studies than disabled men.

Analysis of data collected by the Further Education Statistics Agency reveals that 7% of all students in full time courses of study in colleges of further education in Northern Ireland during the academic year 2001-2002 were disabled. Participation rates for disabled women (49%) were lower than those for disabled men (51%) but higher than women who were not disabled (45%).

Health and Social Wellbeing

The Health and Social Wellbeing Survey, 2001 was commissioned by the Department of Health, Social Services and Public Safety to monitor the health and wellbeing of the Northern Ireland population. Key findings on disability and gender are presented below.

Thirty-eight percent of respondents said that they had a long standing illness or disability that has affected them over a period of time. Twenty-seven percent said that they had a health problem or disability which substantially limits their ability to carry out day to day activities. This latter group has been used to represent disabled people. There were proportionately more disabled women (29%) than disabled men (26%).

Twenty-one percent of respondents were depressed and women (24%) were more likely to be so than men (17%). Disabled people (52%) were much more likely to have experienced quite a lot or a great deal of stress or worry in the 12 months prior to the survey than people not disabled (34%). Women (44%) were also more likely to have experienced a lot or a great deal of stress than men (34%).

Social Activities and Service Provision

The Equality Commission conducted research in early 2002 to examine the extent to which disabled people experience difficulties when using services or social facilities. Disabled people overall were presented with difficulties in undertaking activities such as shopping (29%) going to the cinema, theatre or concerts (18%), going to a leisure centre (18%) and eating out in a restaurant or having a drink in a pub (17%).

There were a number of notable gender differences. For example women (36%) were more likely to experience difficulties with shopping than men (21%). Similarly women (20%) were more likely to experience difficulties with eating out in a restaurant or having a drink in a pub than men (13%). Men (42%) were also more likely to state that they had no difficulties doing any of these activities than women (36%).

The service which presented the most difficulty was public transport with 18% of disabled people reporting a problem with this service. Women (21%) were more likely than men (13%) to experience difficulties with using public transport. Disabled men (58%) were more likely than disabled women (51%) to say that they had no great difficulty using these services.

Awareness levels of the DDA had improved among disabled people (47%) compared to a comparable survey carried out in 1998 (27%). Disabled men (51%) were more likely to have heard of the DDA than disabled women (44%).

Literature Review

Nick Acheson, a research fellow from the University of Ulster, conducted a literature review to provide a synopsis of the relevant literature and to identify issues for discussion within focus groups for this project. What follows is a summary of his report. A bibliography of relevant literature, not all of which is treated in the text, is included as an appendix.

Introduction

This literature review will:

- Consider the comparative social and economic status of disabled women
- Record evidence of the ways disabled women have experienced and negotiated discriminatory processes
- Discuss the development of the concept of double discrimination.

The approach has been to consider the literature on the impact of sexism and disablism on the lives of disabled women. The starting point is the view that both gender and disability are social constructs whose practical result is to structure the lives of women, disabled people and disabled women in particular in oppressive ways (Morris, 1991). Much of the literature on disability derives from medical sociology and is more concerned with the impact of living with chronic illness and particular impairments (Barnes and Mercer, 1996; Thomas, 1997). This literature has little to say to an equality and human rights agenda, but as Thomas (op cit) observes, the distinction is not always made clear.

The Developing Visibility of Disability and Women as an Issue

The particular disadvantage experienced by disabled women remained largely unrecognised until the 1990s. The development of the human rights agenda in respect of disability, which had its origins in the UN Decade of Disabled People of 1983-1992, was substantially silent on the issue. Neither the UN *World Programme of Action Concerning Disabled Persons* of 1983 nor the UN *Standard Rules of Equalization of Opportunities for Disabled Persons* of 1993, made any mention of disabled women (Priestley, 2001). As a consequence national anti-discriminatory and equal opportunities legislation in respect of disability, adopted by many countries in the light of their UN commitments generally, make no reference to disabled women as a group experiencing particular problems.

In 1990, a special Experts Seminar of the UN on disabled women adopted 90 recommendations. These range from policy issues such as education and employment, to personal politics such as reproduction and sexuality and the need to develop an international infrastructure to support the emergence of a disabled women's voice in policy forums globally (Joneken, 1998, p68-69).

Disabled women's organisations participated in the NGO Forum arranged in conjunction with the UN Women's Conference in Beijing in 1995. They made the connection between disability and women's issues and since then there has been more work on "genderising" the UN Standard Rules (Andersson, 1998).

The success of the NGO Forum in Beijing in highlighting the issues faced by disabled women was followed up by an International Leadership Forum for Women with Disabilities held in Washington DC in 1997 and attended by 600 women from 80 countries (Rehabilitation International, 1998)¹. The Forum highlighted as key issues: education; economic empowerment; an end to violence against disabled women; good access to healthcare; and the right to a family life (op cit, pp146 – 150).

The Socio-Economic Status of Disabled Women

Notwithstanding the unreliability of statistics on the prevalence of disability in populations (Oliver and Barnes, 1998), there is a broad consensus in the literature that there are more disabled women than there are disabled men. Thus Martin et al (1988, 1989) found that in Britain the rates of disability for all boys and men was 121 per thousand and for girls and women, 161 per thousand. The numbers of women over the age of 75 accounts for much of this difference. The difference is slightly less for disabled people living at home, 58% of whom were women. A parallel study in Northern Ireland found a similar picture (Smith et al, 1990) and it appears to be generally true elsewhere in the developed world (Rousso, undated).

Disabled women are less likely to be in paid employment than either disabled men or non-disabled women (Martin et al, 1989). In a study conducted in Britain, higher proportions of disabled women were found to be in unskilled work than both disabled men and women who have not been disabled (Lonsdale, 1990). In an overview of the evidence from the United States, Rousso (op cit) concludes that regardless of age or

¹ The Forum Final report contains a useful resources section citing additional literature and other resources such as videos and websites. A copy of the report is lodged at the Equality Commission.

education level, disabled women are employed less than disabled men, and far less than non-disabled women and men.

Disability and Sexual Politics

Asch and Fine (1997) observe that disabled women are less likely than women who were not disabled or disabled men to fulfil the roles customarily reserved for their respective sexes. Not only are their income-earning opportunities severely restricted, but “so too are opportunities to be nurtured and to nurture, to be lovers and to be loved, to be mothers if they desire” (p241). In one of the earliest contributions to the literature on women and disability, the same authors observed that the lack of opportunities to marry and bear children, coupled with difficulties in finding employment, place disabled women in a limbo state they describe as “rolelessness” (Fine and Asch, 1981).

Their approach is supported by research in both Britain and North America. Research in the United States reported five key concerns of the physically disabled women interviewed. These were:

- Lack of opportunities to establish romantic relationships;
 - Disabled women have the same sexual needs as non-disabled women, but less opportunity for sexual activity;
 - The self-esteem of disabled women is linked to their socio-economic circumstances rather than their impairments;
 - Physical abuse is a very serious problem for disabled women, who lack opportunities to escape abusive relationships;
 - Disabled women experience serious barriers to adequate general and reproductive health care.
- (Nosek, 1997).

Nosek (op cit) comments of her own personal experience:

“I am a whole women, but somehow, along the way, I assumed that there were parts of womanhood that were not my own. I was anxious to form relationships, but no one approached me for a date, making me feel like a neutral sex. I was raised to expect that I would never marry, making me feel that family life was not supposed to be for me. I was given little information on reproduction except that it should be avoided at all costs. I can't tell you how many times I was told I should have a hysterectomy. It was always my disability that was more important than my womanhood” (p94).

In a study of women with spinal injuries in Britain, Morris (1989) found a similar state of affairs. These studies consistently show that for disabled women, the prejudicial assumption that they are not women in the full sense in that they can not expect to form loving relationships, have a sex life and have children if they wish, remains a core issue.

Lloyd (2001) comments that the evidence illustrates the ways in which the concerns of disabled women differ from those expressed by disabled men and which were dominant in the early years of the disability movement. Much more than men, disabled women appear concerned with sexuality, reproduction and family life. In this, says Lloyd, they share many of the core concerns of mainstream feminism. But there is the crucial difference that many disabled women are concerned that they are excluded from traditional women's roles. At the same time, the feminist alternative of the "indefatigable career woman" (p718) is often beyond their capacities.

Lloyd is critical of mainstream feminist thinking on motherhood and sexuality as failing to take into account the dilemmas faced by disabled women who have children. Too often, disabled women are denied the choice to have children, "unless and until they can prove that they are capable of fulfilling the stereotypical mother role and function" (p720). She remarks that "The common experience of learning disabled women remains that, even if sterilization is not as routine as it once was, there is rarely any consideration of the possibility that their desire to have children, even within a stable partnership, is legitimate. Pregnancy is more likely to be viewed with a mixture of fear and panic by family and professionals alike" (p720).

Lloyd concludes that the primary discrimination experienced by disabled women arises from society's denial of both their right and their capacity to fulfil the roles of wife and mother.

Commenting on this evidence that many disabled women aspire to the traditional role of mother, Begum (1992) asserts that this is a natural reaction to the position of disabled women as "perennial outsiders" (p73). The role of motherhood confers an otherwise generally denied social acceptability. She argues, however, that because women are defined by a body image socially constructed by men, disabled women get portrayed as defective women. They become subject to the prejudicial assumption that defective women don't have children.

Empirical support for these conclusions has been found by Thomas (1997) in a study of disabled women who were either contemplating starting a family, or were pregnant, and/or had young children. She concludes:

“Disablism was evident in a number of ways: with the women’s close encounter with the medical risk discourse with its unspoken evaluative assumptions that, for example, to give birth to a disabled baby is to give birth to a life of lesser worth. This could entail living with the fear that one might be judged to be an inadequate mother, and that actions might follow involving the denial of the right to be a mother. Furthermore there might be disempowering encounters with (usually well-meaning) health and social care workers who frequently offered inappropriate help informed by a professional ethic that ‘we know best’” (p640).

Women and Disability and the Concept of Double Oppression

There is widespread agreement in the literature about the marginal status of disabled women and that as a group, they do less well socio-economically than disabled men. There is, however, less agreement on the significance of the evidence.

Some writers suggest that the experiences of disabled women are not that dissimilar to women in general. Thus Lloyd (1992) suggests that the differences between disabled and non-disabled women’s employment are less than the differences between disabled men and men who have not been disabled. She concludes that the “disadvantage, discrimination and inappropriateness of employment structures which disabled people encounter in their struggle for paid employment are *faced by women anyway* as an inevitable consequence of their gender” (op cit, p210; emphasis in original). This leads her to suggest that the disadvantages of disability and being a woman compound each other (Hanna and Rogovsky, 1991). She argues that an analysis of the circumstances of disabled women that ignores the ways in which they are also the objects of sexist social attitudes and practices must be inadequate.

However, the concept of “double oppression” in this context has been judged as not very helpful by some disabled analysts (Morris, 1991, 1996; Shrdon, 1999). It opens up an unanswerable question as to what oppression comes first. Is a disabled woman to be viewed as a woman who is also disabled, or as a disabled person who is a woman? Writing in the context of disability and racism, Stuart (1993) suggests that the notion of simultaneous oppression is a more fruitful approach. He argues that black disabled people’s experience is qualitatively different to either non-disabled black people or white disabled people.

Jenny Morris (1996) comments that people’s lives are not fragmented into separate analytical categories. Writing of her own experience, she says: “Before I acquired a physical impairment, it was sexism that dominated my

interaction with the public and private world: now it is other people's reaction to me as a *disabled* woman which structures my experience" (Morris, op cit, p3 Emphasis in original).

She argues that a focus on double disadvantage "can only feed into the negative attitudes of those 'feeling sorry' for us" (op cit, p4) and is critical of writers such as Lonsdale (op cit) and Lloyd (op cit). She argues that they have placed too great an emphasis on the uniquely disadvantaged status of disabled women.

Vernon (1996) studied the experiences of black disabled women in Britain and concluded that they experience a multiplicity of barriers resulting from a combination of sexism, racism and disablism. But as one of her interviewees explained, "it happens singly, plurally and multiply, and it's the totality that counts at the end of the day. You are thought of as completely inferior because you are all three things" (op cit, p68).

However, the evidence suggests that how disabled women feel about being women is informed by their experience of an assumption (that is frequently made explicit) that they are less than women. This is particularly evident in the sphere of reproduction and sexuality, but it is not confined to that sphere. It can also be apparent in everyday interchange between men and women when the woman, or at least one of the women, happens to be disabled. Morris (1991) offers a personal anecdote that illustrates the way that the disabled identity tends to subvert any feelings of solidarity between non-disabled and disabled women in the face of sexism among men. In the end, negative feelings about disability among able-disabled people of whatever sex, are more powerful forces in social interaction than solidarity among women as women.

Women, Feminism and the Social Model of Disability

That the majority of disabled people are women has led Jenny Morris to observe that disability is a women's issue, "yet the experience of disabled women has been largely absent from feminism's concerns and, within the disabled people's movement, has tended to be tacked on as a 'special interest'" (Morris, 1996, p1). The marginal way disability has been treated as an issue within the women's movement, and the marginal place of disabled women's experience and analysis in the disability movement has been a significant theme in the literature on women and disability during the 1990s (Begum, 1992; Lloyd, 1992, 2001; Morris, 1991, 1996).

All these authors accuse mainstream feminism of ignoring the experiences of disabled women. Morris (1991) mounts a furious attack on those

feminist writers who in the 1980s had suggested that any form of community care was sexist and that therefore dependent people should be looked after in institutions. She accuses such feminist writers for forgetting that the majority of people being looked after are also women.

She later argues that subsequent research on community care has remained committed to a dual paradigm of carers and dependent people. An unwillingness of researchers to listen to the voices of disabled people whose personal care needs may be met by relatives, amounts to collusion in the prejudice that disabled people's lives are "not worth living" (Morris, 1996, p6).

Keith and Morris (1986) round on carers' interest groups, the media and researchers who construct the children of disabled parents as 'young carers' and their parents as dependent. In this paradigm, as with the case of adult carers, the social problem is constructed as relieving the burden of caring. Keith and Morris cite poverty, disabling professional attitudes, disabling services, and disabling environments as among the causes of the difficulties faced by disabled parents. The authors conclude that the identification of 'children as carers' has far-reaching and potentially devastating consequences for many disabled parents. "This is the fear that all disabled or ill parents live with: are we considered 'good enough' parents and if not, is someone going to 'rescue' our child/ren from the 'burden' of having an ill or disabled parent?" (op cit, p112)

Both Morris and Lloyd are critical of the feminist slogan of 'the right to choose' as implying that women should have the right to choose not to have a disabled child through abortion. Morris (1991) notes that this assumes that disabled lives are not as valuable as the lives of people who have not been disabled. Lloyd (2001) terms this a "rather cavalier assumption" (op cit, p719) and thinks there is a lack of commitment in feminism to open up the layers of ethical, philosophical and socio-legal debate.

However, the willingness of feminism to address issues of personal experience has lead disabled women writers to seek to modify the early versions of the social model of disability that emphasised a strictly social basis for disability. (UPIAS, 1976; Oliver, 1990, 1996). Along with Morris (1991), French (1993), Crow, (1996), Corker, (1998), and Thomas, (1999, 2001) have all insisted that personal experience of discomfort, pain and restriction must be accommodated for adequate theories about disability.

The tendency to focus on personal experience among writers on disability informed by a feminist perspective is open to criticism. Finklestein has argued that focusing on experiences is a "discredited and sterile approach to understanding and changing the world" and calls for a return to clear

focus on the structural aspects of the social system. A focus on experience, he argues, leads to a passive interest-based form of pressure group politics and undermines the making of common cause with other oppressed groups. (Finklestein, 1996, p34; cited in Thomas (2001))

More relevantly for the research agenda under consideration here, Sheldon (1996) argues that such an approach adopts a very narrow view of feminism and is critical of those who use the 'personal is political' slogan as a basis for foregrounding individual experience. She suggests that only by moving beyond descriptive accounts of individual women, will it be possible to find common ground between different oppressed groups. This suggests that research strategies that rely wholly on personal testimony may miss the significance of the social context out of which that testimony is given.

Discussion

The literature on differentials in the labour market's treatment of disabled women in contrast to either disabled men or women who are not disabled is fairly thin, although there is a clear consensus view that disabled women do least well of all these groups. There is a clear distinction to be drawn in their analysis of disability between male and female disabled writers. The male view, paradigmatically if perhaps unfairly represented by Mike Oliver's seminal book, *The Politics of Disablement* (1990), looks to the operation of the labour market as the key to understanding the structuring of disability as a form of oppression. Women disabled writers, on the other hand, influenced by the feminist slogan, 'the personal is political' are much more concerned with inter-personal relationships, sexuality and reproduction. The evidence from research over the past 15 to 20 years may be a reflection in part of the interests of the researchers. But there appears to be sufficient breadth in the literature available to suggest that Lloyd's conclusion, that the primary discrimination experienced by women is around sexuality and reproduction, may have some basis. Disabled women in general focus on these core personal issues when they identify what is most disabling for them in contemporary society.

The literature suggests that the reasons for this are that disabled women, because they are women, are more vulnerable than disabled men to the role of dependent and helpless victim. This imposes a no-win situation on disabled women who see their only chance of escape into an acceptable woman's role through sexuality and motherhood, the very role that their assumed dependence denies them the right to and capability of. One might argue that work and labour market participation would figure a long way down the priority list for women who cannot have a sex life and are

denied the choice as to whether or not they may have children. Feminist analysis has made it clear that economic independence for women in general depends on their control over their sexuality and fertility. This is no less true of disabled women than of other women. On this count, the evidence is that as a result of prejudicial attitudes, too many disabled women are not even at the starting block.

Conclusions

In the light of the literature, useful research into what it means to be a disabled woman should have, as its primary focus, the issues that have been shown to be uppermost in the minds of disabled women in this respect. The core issue here is the experience of sexuality and motherhood. Although evidence of women's experience of work and related training schemes should also have its place, on its own, the literature would suggest it would miss a large part of the experience of being a disabled woman.

Focus Group Report

As identified in the Introduction this project involved focus groups with disabled women and representatives of the health sector. This section summarises the findings of the focus group discussions; the focus groups with disabled women are dealt with first followed by the health service focus group.

Individual focus groups with disabled women were facilitated by Equality 2000 (Dungannon and Armagh), STEER (Derry) and the North West Forum for people with disabilities (Derry).

Selection of participants

The literature review recommended that participants for the focus groups should be drawn from a range of impairments and a range of experiences. These might include women with visual and hearing impairments, women with various physical impairments, and women with mental health problems. The sample should also include mothers and women who are not mothers, women in long-term relationships and women who are single.

A fundamental aspect of the focus groups was to include women who were aware of equality and discrimination issues. However, it was also considered important to include women who ordinarily did not have a voice. Such women may not necessarily be aware of equality issues.

Focus group facilitation

Due to the anticipated personal emphasis of the discussions it was considered necessary to engage independent facilitators to navigate the discussions. It was important that facilitators were women with whom group participants were familiar and/or felt comfortable with. The facilitators were each recommended by the individual groups and all three had experience of disability either personally or through family or community connections.

Nature of discussions

The literature review identified a number of issues to be addressed in the focus groups. These included: -

- Personal and private relationships; accessing health service; attitudes to and experience of having children; impact on personal choices; nature and impact of caring relationships; other significant issues and barriers.

Characteristics of Participants

Self described social class	Neither working nor middle class	11
	Yes, middle class	2
	Yes, working class	3
Marital status	Single	9
	Living with partner/married	6
	Divorced/separated	2
Age group	16 to 24 years	1
	25 to 34 years	6
	35 to 44 years	6
	45 to 54 years	4
Educational qualifications	No formal qualifications	5
	CSE other than grade 1	1
	GCSE and equivalent	3
	Degree or higher	8
	Other qualifications	2
Age when completed continuous full time education	17 or under	5
	18	5
	19 or over	6
	Returned to education	4
Current activity (N > 17 due to multiple response)	Full time carer	2
	Looking after the home	3
	Doing paid full time work	4
	Doing paid part time work	2
	Voluntary work	7
	Not working (seeking work)	1
	Not working for health reasons	4
	Not working & not seeking work	3
	In full time education	2
Participants with children	Yes	10
	No	7
Nature of impairments	Deaf or hearing impaired	2
	Physical disability	9
	Mental health problem	5
	Unseen disability	1
	Blind or partially sighted	2
	Progressive disability	2
Length of time living with impairment	Birth	8
	Childhood	2
	Early adulthood	7

Women who were in paid full time or part time work were all in permanent jobs. Participants currently and in the past were employed in a range of occupations including administration, sales, driving, catering and teaching.

Gender and Disability

As a starting point to the discussions participants were asked to consider how they felt they were perceived as women by wider society. Participants felt that women were capable of achieving in school, gaining employment and accessing services. Participants in all groups felt that women are treated less favourably than men in terms of expectations and also in relation to service provision: For example many related that women are expected to “*sort children and home first and then they can get a job*”. Many also felt that there is an assumption that women are the weaker sex and none of the participants agreed with this assumption. There was also consensus that “*everything you do as a woman is an issue*”, that for example in using the services of a garage or buying bricks, the service provider presumes that women are less knowledgeable. It was also felt that women put too much pressure on themselves to achieve all that is expected of them.

The groups then went on to discuss how they felt they were perceived as disabled people. Some participants did not consider themselves as disabled, but following a social model definition of disability they all agreed that they have been and continue to be disabled by discriminatory practices and negative attitudes. The majority of participants believed that they are disabled by societal and environmental factors.

There were wide-ranging responses to the question, “How are you perceived as a disabled person?” covering attitudes to disabled people and the denial of rights. There was consensus that disabled people are patronised with one participant often being told “*You’re great*”. Some participants said that they felt more comfortable in the company of other disabled people; for example, whilst undertaking training because they did not feel excluded. Many said that socialising in mixed company (that is disabled and not disabled) could often be a negative experience with some saying they have been “*side lined*” and “*ignored*”. One participant said that she prefers to go out alone as she has found that “*People have to talk to me whereas if I am with someone else people tend to ignore me or talk to me through my companion*”. One participant felt that disabled women are not expected to be assertive, as she said, “*Women have to assert themselves to gain respect and then others are surprised to find out that this assertive woman is disabled*”.

Many participants identified with issues of discrimination faced by women and also with discrimination towards them as disabled people. The majority believed that it was how they were treated as disabled people, which was the more important of the two issues. As one participant said “*You have to sell yourself that bit harder and this has been throughout my life, I have*

experienced discrimination from both perspectives". Another woman felt that she is perceived as a "*handicapped girl*". Finally one woman said she is "*firstly a woman and then she is disabled, the issues are around womanhood first*". Another participant disagreed she felt very strongly that by putting disability second it would be "*like denying or negating part of my person / my existence, it would be denial of something very important and fundamental*".

Personal and Private Relationships

Participants were asked to talk about their experience of personal and private relationships. Many of the women said that they tried to hide or denied they had an impairment during their teenage years so as not to appear different and avoid the stigma. For example one woman said she often did not wear her hearing aid when going out and relied on lip reading. Some women also said that if possible they would continue to pretend they were not disabled, as "*You are treated differently once people find out about your disability*". Another woman said, "*People think you have no right to meet someone*".

Women who have been disabled from birth felt a number of factors have influenced this aspect of their lives, such as where they socialised in early childhood and the attitudes of their family. For example women who had attended segregated schools felt that these schools were not supportive of their needs and had low expectations of them not only in their standard of education but in other aspects of their lives. They believe that these low expectations have permeated their own expectations for themselves.

Others who had attended mainstream schools shared similar sentiments saying that low expectations had contributed to low self-esteem and "*feelings of worthlessness*". These feelings were aptly summed up by one participant who said, "*Disabled women often have low expectations of their partner because they need to be grateful for whoever they get, rather than be left on the shelf*".

Those women who were not in a long-term relationship said that this was due to over protective family members. As one participant stated, "*I have a close friendship with someone but that is all it will ever be. The big issue for me is my family who feel they need to protect me from the potential hurt of when relationships break down.*" Another participant said that since she has been disabled her family are very protective and do not want her to get involved with anyone because they think she "*could not cope with the hurt/pain that a broken relationship would cause*". Whereas she states that, in previous years "*I was left to live my own life*".

Other women who have been disabled since early adulthood have had similar experiences of low self-esteem and consequently staying with abusive partners. One woman said that her first marriage ended because her then husband could not cope with her impairment. She said, "*He was very abusive and the relationship, especially his treatment of me seriously damaged my self esteem*". She is now in a new relationship with a very supportive partner.

A number of women also felt that partners of disabled women are perceived as carers and that this assumption is detrimental to their relationships. Others currently not in a relationship said that this assumption impacts on their opportunities to form new relationships. Many felt that there is not enough support and/or information for partners of disabled people and that this lack of support makes partners assume a caring role.

Accessing Health Service

When asked about their experiences in accessing health care the discussions were again wide ranging. Some participants felt very passionately and had a lot to say whilst others had less to say perhaps because they had little need to access health care.

A very common theme was that many participants felt that negative attitudes were a major barrier in terms of health service provision. This was evident from one participant who attended her doctor's surgery for a general health check, part of which was to be a cervical smear. She was told that as she did not have a boyfriend she did not need a cervical smear. This participant was very angry at what she believed to be patronising treatment and other participants agreed when she summed up by saying, "*They would not ask a woman who is not disabled if she had a partner, it is just presumed that a disabled woman is not sexually active*".

One woman told how she had contacted a specific health service department to arrange for repairs to be carried out on her wheelchair. She said that the person she spoke to on the phone appeared to be shocked and asked "*Has the wheelchair been vandalised*" to which our participant replied "*No it has just been used, what did you expect me to do with it*".

Yet another participant told how she had attended the doctor's surgery for a postnatal check up, part of which was to be a cervical smear. However the bed or couch was not accessible and the woman was told that the situation would be addressed and that she would be advised of another appointment

date. That was ten years ago and she has never been contacted. This participant has also experienced difficulties in finding a dentist, optician and chiropractor, which are accessible. When she phoned a number of dental practices to ask if the building and treatment room were accessible, she was asked why did she need this facility. She summed up her feelings by saying, "*Why do we have to divulge our personal details of our impairments in order to get a service, this is outrageous*".

In general other participants felt that certain services which would be of benefit to them were not available, such as cognitive therapy and access to counselling. Others felt that the centralisation of services in Belfast was detrimental. There was recognition amongst participants that lack of staff and other resources was contributing to this but there was also agreement that this needed to be addressed. Some participants did feel that health service staff could be positive in their attitude to disability, such as their general practitioner. However they said that this was luck or that it had taken them a long time to find a supportive family doctor. Four women said that they found attending the health centre and/or hospital very stressful because of the long queues and negative attitudes; and one woman consequently avoids seeking medical help.

Should Disabled Women Have Children?

Focus group participants were asked to relate their experience of having children, if they had children, and more generally did they think that disabled women should have children. A number of women did not have children and had no desire to do so. Others without children were unsure as to whether or not they should do. In contrast some women felt very strongly that disabled women should have children as this was their right and that they should be provided with the necessary support to do so. A number of the women had been told by health professionals not to have children for reasons related to their disability.

There was consensus among participants that disabled women are not expected by wider society to become mothers, and when they do they face criticism. One participant said that "*Disabled women are thought of as needing care and are not envisaged to have children or a relationship*"; this was echoed by many of the women. One woman who said that she had received adequate antenatal care and good support around childbirth from the medical profession was then criticised by a social worker for "*having too many children*"; she had three children. Another woman was criticised by a gynaecologist for becoming pregnant because of the risk of "*passing on my visual impairment and the risk of learning disability from my husband's family*".

Many participants feel this attitude is widespread among doctors and wider society especially among women who are not disabled. A woman who has one child is often asked if she is going to have any more children and as she said, "*People are really shocked when I say that I am not sure*". She feels that the people who ask her this question have already decided the answer should be no.

Many participants believe that disabled women feel that they need to ask permission to have children, when what they are looking for is the necessary support. One woman said that, she felt 'normal' when she became a mother and others agreed that the right to this experience should be available to all disabled women. A number of participants stated that they would like to have children because doing so would boost their self-confidence and self-esteem as a woman. Another participant said that she was shocked at the support she had received from her general practitioner who had advised her to consider fostering children. She had previously believed that disabled women would not be allowed to foster.

A participant related that a few years ago she and her husband decided not to have any more children. They requested that her husband be put on the waiting list for a vasectomy. As a couple they had great difficulty gaining medical consent for this operation to be performed. Their doctors were prepared to sterilise her despite the fact she was younger than her husband, and medically unfit for the operation. She believes that the reason for this inadequate service lies in the discriminatory attitudes of the doctors whom she believes considered that, as a disabled woman, she should not have any more children.

Impact on Personal Choices

The literature review recommended that participant's self-understanding as women should be explored. This issue was addressed by asking participants what personal choices they had made and to consider what approaches they have adopted to living life as a disabled woman.

Some women said they did not and could not access certain services such as routine cervical smear tests as this was inaccessible and they have given up trying. One woman said she had succumbed to pressure from close family and doctors to be sterilised and with hindsight she regrets this decision. A few women said that they did not want to have children, as they believed they "*could not cope with the physical and emotional demands*" having a child might place on them.

Many participants said they had to fight, struggle and refuse to take “*bad treatment*” to get the service they needed or be treated differently, as one woman said, “*You have to be very stubborn with your family to do your own thing*”. Speaking of service providers in the health and social services one woman said, “*You need to hassle them all the time otherwise they forget about you*”. This woman resented having to behave in this way. A number of women also said they pretended, where possible, not to have an impairment; as one woman said “*Once some people find out that you have a hearing impairment their attitude toward you changes*”.

In contrast another participant said that she has adopted a very open and honest attitude to her own impairment and those of her children. She has decided to tell her children as much as she knows about disability so that they can make informed decisions about their own lives. She feels she was denied this when she was growing up and blames the medical profession.

One participant has been told that hospital treatment she requires to stabilise her medical condition is having a disruptive influence on her children. This information is being used to support the case for custody being awarded to the father. This woman feels that her role as a mother is being undermined and she said, “*This battle has made me stronger because I have had to learn to fight but there are times when I am very fearful*”.

Many women said that they have learnt to identify alternative sources of support and information, such as voluntary groups and other disabled people. One woman told how “*It was pure luck that I got a different doctor who started the process of finding the support mechanisms I needed, I was then in a position to seek out my own support*”. Another woman told how she had avoided the medical profession for nearly 20 years because of negative attitudes. She said, “*You have to go very far down before you get the support you need, this should be available earlier in illness*”. This woman felt that she has lost out on years of her life.

There was agreement among participants that the environment in which disabled people grow up is very important. One woman was brought up in a family where she and her siblings were disabled. She did not feel different and her parents were very positive making adjustments in the home. She feels this positive and supportive start has enabled her to fight for her rights.

Finally one participant feels that it is important for disabled people to recognise their limitations and then source and use the support they need. She said, “*I was a carer to my two disabled children and it was only when I*

got the support I needed that I could begin to parent them and be their mother”.

Nature and Impact of Caring Relationships

When participants were asked to discuss their need for personal support, some referred to the complexities of care within their family and others raised again the issue of over protective families “*interfering where they weren’t wanted*”. However many participants referred to the lack of care they received from state agencies.

One participant summed up the views of many others when she said, “*Service providers (particularly social services) consider other family members of disabled people as carers and therefore prevent disabled people having a decent and independent life*”. This woman highlighted an example in which she said that social services would not fund the provision of personal support for her because they felt that her husband should provide this. This participant was particularly frustrated by this decision as she was denied choice in, for example, what she ate and the temperature of the room she occupied as her husband had to leave previously prepared food in the fridge and fuel the fire so that it would last all day.

A few participants remained in abusive relationships because their then partner was their main carer and they felt they could not leave these relationships because of the lack of care provision by the state. These women did leave these relationships when they had identified alternative care arrangements from family and friends. However they felt that they are denied the opportunity to lead an independent life. There was a consensus among participants that many disabled women stay in abusive relationships because of a lack of care alternatives.

A participant said “*I cannot take my children to the dentist or attend their school to meet teachers*” because of inaccessible premises. She feels that she is being denied her rights as a parent and unable to fulfil her aspects of her caring responsibilities. Another participant said that because almost all service providers do not provide sign language interpreters she could only access services through a family member. This lack of confidentiality is particularly difficult when for example, attending the doctor.

Finally one participant said that she is frustrated by the fact that her parents depend on receipt of certain means tested benefits to provide her with the personal support she requires. They are reluctant for her to get a job because they believe she would not earn the equivalent of these benefits. She said, “*Children who are not disabled are not in this trap*”

Other Significant Issues for Disabled Women

Participants were asked if there were any other issues which they considered. Many issues were raised and these broadly fell into two categories, attitudes toward disabled people and lack of opportunity in areas such as education, employment and service provision.

Many of the women felt negative and patronising attitudes toward disabled people was detrimental to them in all aspects of life. One participant said, *“A big issue for me is ignorance and rudeness of others, particularly people who stare”*. This participant and many others believe that embarrassment and lack of information continue to surround disability and this includes health professionals. As one woman said, *“very difficult to get the service and this is due to negative attitudes and lack of training and very poor awareness”*.

Many felt this could be addressed through extensive disability awareness training, which should begin in schools and continue through to employers and service providers. There was agreement that, *“this training should be rights based”* and informed by the social model of disability. There was consensus that training, particularly in schools, should not be a one off event but should be part of the curriculum. As one participant said, *“Awareness early in life could prevent a lot of mental ill health in later years”*. There was also support for all children being educated together in the same schools as long as the needs of disabled children are fully met.

A number of participants felt issues for disabled people were perceived differently to those for women in general; as one woman said *“The trade unions consider women’s equality as a right but disability is not seen as a rights issue”*. Finally some participants felt that disabled women have a role to play in changing negative attitudes. As one woman said, *“I do not want to be seen as a charity case. As disabled people we have a responsibility to demand our rights and stop apologising”*.

A variety of access issues were also raised as important. These included: -

- accessible parking
- accessible aisles and shelves in supermarkets
- scan machines in hospitals should be accessible for visually impaired people
- cash machines should be accessible for wheelchair users and for visually impaired people

There was substantial debate about education and access to employment. As one woman said, *“The system is difficult to fight, particularly when looking for a job”*. Many felt their education had not prepared them for the

labour market and those who have been disabled from early adulthood had to leave employment because their employers were not supportive of their needs and in some cases this caused further ill health.

All of the women agreed that there is a lack of investment in the health service. Many felt that the poor service provision they experienced was due to lack of staff and other resources. There was also agreement *“that professionals have very poor information”*.

Health Sector Focus Group

A focus group was organised with representatives from the health sector and participants were identified through an equality network within health and social services in Northern Ireland.

There were representatives from a number of hospitals and health and social services trusts. Participants were mostly from social services with the exception of one doctor who works in family planning services. Other participants included social workers, equality schemes co-ordinators, disability services manager, human resource managers and a development officer for mental ill health. Participants were encouraged to share not only official policies but also their own personal feelings about service provision for disabled women.

In Northern Ireland public authorities are under a statutory duty to promote equality of opportunity in terms of employment and service provision and consequently are required to produce an equality scheme to be approved by the Equality Commission. This duty has been placed on public authorities by Section 75 of the Northern Ireland Act, 1998. Many of the participants used the opportunity of the focus group discussion to demonstrate their commitment and effort to meet these requirements.

Disability Awareness

Participants were asked to reflect their attitudes to disability and whether they had received any disability awareness training. One participant said that her employer had provided a half-day training for 2000 people. She felt that *“this training had influenced and changed attitudes”* particularly so as *“the training had been delivered by a disabled person”*. This health trust had also included a leaflet in the pay packets of all staff entitled ‘What does the Disability Discrimination Act (1995) mean to you’. This was considered an effective way of getting information to all employees as not all could

avail of training. Many participants stated that not all of their colleagues were supportive of taking time to participate in disability awareness training.

There was then lengthy discussion around various types of disability awareness training as one participant said she had received a different style of training 20 years previous, which had involved becoming temporarily blind, deaf and/or a wheelchair user. Many disabled people believe that this type of 'stunt' training does not accurately reflect their situation. Focus group participants agreed and many advocated disability awareness training should be provided by a disabled person and informed by the social model of disability. A few participants felt that it is easier to relate to the issues faced by disabled people if you have a family member or friend who is disabled and therefore have personal experience.

Many participants raised concerns about sources of funding for the provision of training. These included the fact that disability awareness training generally was "*not included in priorities for action*" and certainly issues specific to disabled women "*were not on the agenda*". As training is not prioritised it was necessary "*to find money from elsewhere to provide training*" and this is extremely difficult.

A number of people felt that "*changing individual attitudes is important but real change needs to come from higher up*", so that issues can be prioritised. For example, no money appears to have been prioritised to address a further duty under the DDA to remove physical barriers by 2004. One participant said, "*Disabled women are not on the agenda, in particular women with mental ill health. The focus is on crisis, for example if someone becomes mentally unwell they have to become severe to get support*". She continued, "*There should be a holistic approach to providing support and there should be more investment in preventive services*".

A few participants said that their awareness of disability issues had been improved through general equality training specifically around the statutory duties placed by section 75. Many felt that these duties have raised awareness of equality issues in general. However there was no money available, for example to ensure service provision is accessible. As one participant said "*Progress reports relating to accessibility have to be provided and evaluated by the Board and the Equality Commission, but there is not enough money to do what is necessary*". Other participants referred to access audits having been undertaken and soon to be completed. There was an expectation that "*disability access will cost millions*". Yet another participant said, "*I am working through the equality impact assessment for recruitment and as this is very new work it involves a steep learning curve.*"

Participants were asked to consider if they thought people working in the medical profession made judgements about the quality of life a disabled person could lead. One participant said, "*Professionals are judgemental and this applies to everyone not just to disabled women*". She continued, "*People in service provision are under tremendous pressure and given unrealistic deadlines*". She concluded by saying that "*There is not enough funding for access issues and this is not the responsibility of individual doctors*". There was general agreement with another participant when she said, "*Prejudice is deep rooted, we can be professional but deep down we do not agree*".

Specific Issues for Disabled Women

The discussion then moved on to ask participants to reflect whether the health trust they represented had a policy on contraception for women with a learning disability. A number of participants recognised that some women with a learning disability are denied access to sex education generally and choice in terms of contraception specifically. One participant said, "*Each case would be individual and there would be no blanket policy or stance*". A number of participants said that they were aware of discussions taking place within their trusts in relation to the sterilisation of women with a learning disability but that they were not part of this decision making process.

Participants were asked to consider some issues raised through the focus groups held with disabled women, such as having children and access to specific services. Overall there was agreement that disabled women should not be prevented from having children and there was recognition of the needs of disabled women in this respect. However a number identified potential problems in addressing any support needs a disabled woman might have when she becomes a mother. As one participant said, "*There is a lack of support, it is a minefield, I need to apply to child services for the baby and also to adult services for a mother with an impairment*".

The discussion embraced the issue of older children providing care. One participant said that a mother (who was a wheelchair user) of a six year old had a second baby. The older child was given caring duties and this participant felt this was abusive of the older child. However another participant said she would never "*factor in a young child as an extra pair of hands, but it is unrealistic to expect other family members not to assist. But they should be viewed as family and not carers*".

When asked to consider the situation when a wheelchair user was denied a smear test because there was no accessible bed/couch, many participants

were surprised to learn that this had actually occurred. One participant said, *“if a woman needs a smear test she should go to her general practitioner and each case would be examined individually”*. The doctor who participated in the discussion relayed how she had treated a disabled woman the previous day and was prevented from providing the full range of services because of access issues. She said that access is a major issue and she has been trying for years to secure a facility which has accessible parking, is staffed by people who are trained in disability awareness and that beds and cubicles are accessible.

The doctor from the family planning service felt very strongly that attitudes to abortion need to be challenged. She said that, *“Doctors readily terminate a pregnancy if there is a risk of the child being born with an impairment but are unwilling to do so otherwise. These doctors believe they are relieving the woman of the burden of a disabled child.”*

Throughout the discussion it emerged that it is difficult to get senior staff and general practitioners in particular to attend training due to the fact that they cannot leave their practice as this would put additional pressure on remaining staff. There was consensus that there are major cost implications in providing training as additional resources need to be provided to allow training to take place. Group members exchanged advice on how to get GP's to attend equality training by for example including such training as part of regular update training. A few participants also said that health service staff are expected to attend a lot of training (disability, health and safety, equality and human rights issues) and this puts even more pressure on their time.

Many participants relayed that they undertook research projects such as customer satisfaction surveys, organised user forums and engaged in various consultations in relation to service provision.

Participants were asked to consider if looking at people from a multiple identity is missing out on important aspects of people's lives. Many had not thought about this and as one group member said, *“The new legislation is forcing me to look at people per se and not at individual situations.”* Another participant said of the trust she works for, *“We provide service for all who need service and if a complaint is made then plug the gap for all and not just for the complainant”*.

A major thread running throughout the discussion was the issue of a lack of resources and that work on the ground could not develop without prioritised resources. A number of participants argued that recent employment trends such as offering employees reduced hours were contributing to staffing shortages, as the shortfall in hours was not being replaced.

Many also expressed disappointment and frustration with the Northern Ireland Assembly at Stormont as they believed the members of the Assembly had a potential role to change health service provision but “*this has not happened*”.

Many participants initially felt that they may have had little to contribute as they had not previously thought about some of the issues. In contrast many said that they had gained and learnt from the discussion.

Conclusions and Recommendations

People's lives are influenced and structured by many factors including their gender and whether or not they are disabled. The lives of women and the lives of disabled people are structured in oppressive ways. Are the lives of disabled women in particular structured in oppressive ways?

The equality movement generally and governments, in particular, make little reference to disabled women as a group experiencing specific problems. This is evident within the relative lack of available data and the relatively rare research focus. Where there is such reference (International Leadership Forum for Disabled Women 1998) the key issues identified are:

- Education
- Economic empowerment
- End to violence against disabled women
- Good access to health care and
- The right to a family life.

This research has highlighted a number of facts in relation to the situation, experience and identity of disabled women in Northern Ireland. They were more likely to participate in higher education than disabled men. However disabled women were less likely to be in paid employment than disabled men and women who were not disabled. In addition disabled women were more likely to experience difficulties accessing certain services and social facilities than disabled men. Disabled women are less likely to fulfil the roles reserved for their sex, "*to be nurtured and to nurture, to be lovers and to love, to be mothers if they so desire*". This rolelessness described in the literature is born out by the statistics and was the actual experience of focus group participants.

Disabled women reported that they receive inadequate levels of support from statutory bodies and that necessary support (for themselves and their dependants) is often found amongst other disabled people, usually other disabled women. Many disabled women have encountered discriminatory attitudes from wider society in general and from health service professionals in particular. Some women reported difficulties in accessing specific health related services.

The literature also raises the question of double oppression and the difficult question as to what comes first; a woman who is disabled or a disabled person who is a woman?

Focus group participants did shed some light on the issue of double oppression, by reference to the time at which they became disabled. Women who have been disabled since birth emphasise their early consciousness of the oppression related to their impairment. However for those who became disabled in early adulthood the emphasis of their sex formed their early consciousness, but from the time they experienced disability the oppression of disablism especially in terms of others reaction to them dominates their experience.

Examination of the situation and experience of disabled women will help the development of equality strategies by furthering the debate around double discrimination and/or multiple identity. Specifically this research has identified a hierarchy of discrimination experienced by focus group participants. The majority of the disabled women who took part in this research said that considerations around their gender came second to living with the consequences of disabling attitudes, environmental and organisational structures. This research has shown that there is significant work to be done in eliminating the disadvantages faced by disabled women in Northern Ireland to achieve equality.

The equality agenda will be advanced through richer empirical data to inform the policy debate. This data will be improved through larger samples enabling more reliable sub sample analysis. In addition the use of a consistent definition of disability (informed by the social model of disability) should be promoted. The data collected for equality impact assessments, undertaken by public authorities will also assist with this debate.

Equality strategies should continue to work to improve awareness of issues specific to disabled people in general and disabled women in particular. The fundamental issue for all those who participated in this research is the need to change attitudes toward disability, from a charitable focus to a rights based model.

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