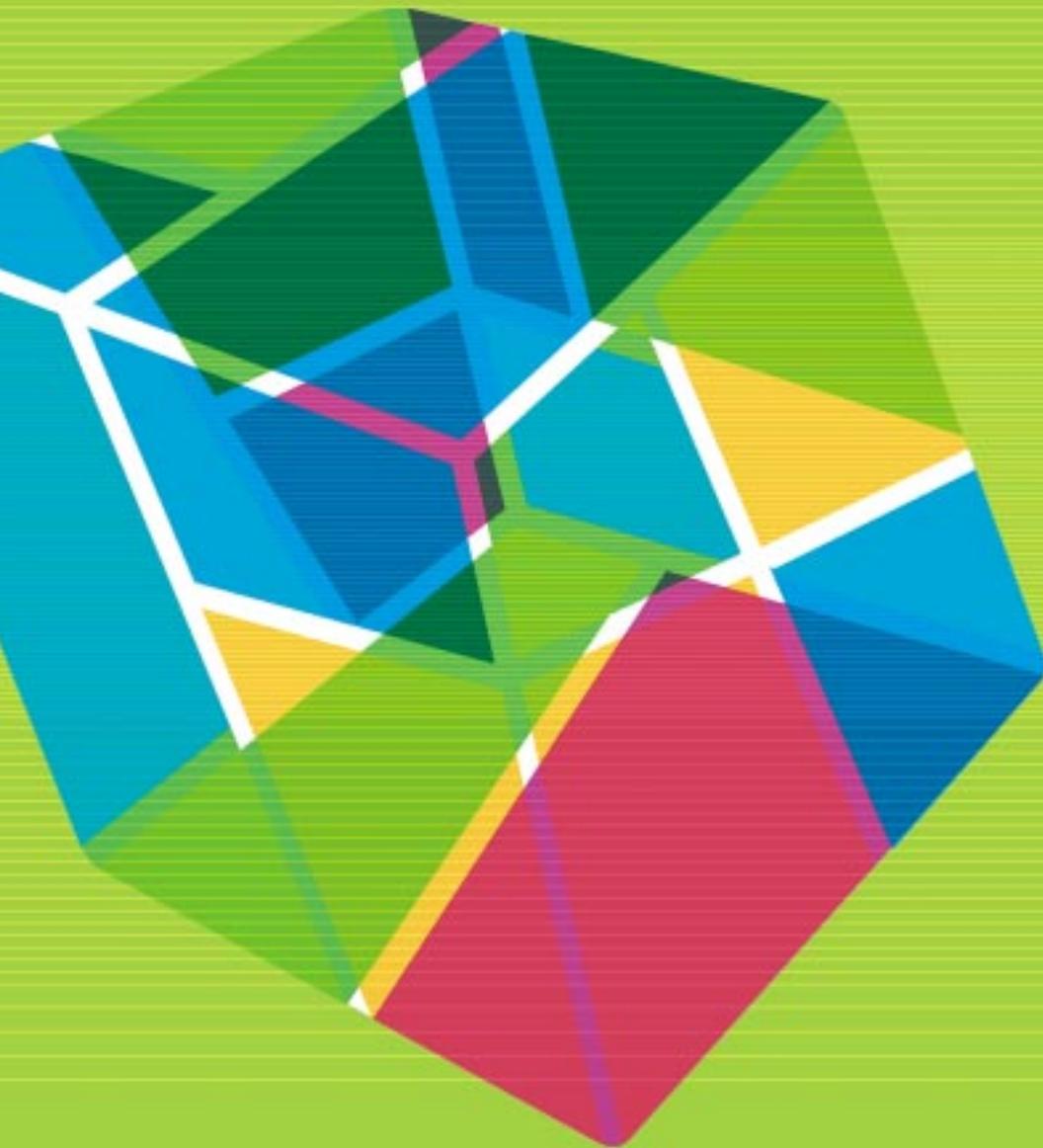


RE-THINKING IDENTITY

The Challenge of Diversity



Edited by
Katherine Zappone

RE-THINKING IDENTITY

The Challenge of Diversity

Edited by Katherine E. Zappone

Commissioned by the Joint Equality and Human Rights Forum

FOREWORD

This publication is the first joint venture of the Joint Equality and Human Rights Forum. The Forum brings together the human rights and equality bodies in Britain, Ireland and Northern Ireland. The cooperation being developed within the Forum seeks to support new thinking on equality issues and to advance the establishment of increasingly effective equality strategies. The exploration of identity and how people hold multiple identities has been a key dimension to this cooperation since the Forum began its work.

The purpose of this joint research project is threefold:

- To accord a visibility to groups of people whose identity, situation and experience has yet to achieve an adequate focus in equality strategies.
- To contribute to new thinking about and understandings of equality on the basis of an exploration of the multiple identities that people hold.
- To open a debate on the practical implications for effective equality strategies that flow from the specific experience, situation and identity of particular groups of people holding multiple identities.

Tackling discrimination and addressing equality issues relating to a particular individual identity remains a key task. However, consideration and action in respect of multiple identity groups is also of major importance and holds significant potential for equality strategies. The research is based on an acknowledgement of the multiple identities people hold. The research focuses on disabled minority ethnic people, Black and minority ethnic women, lesbian, gay and bisexual people with disabilities, women with disabilities, young lesbian, gay and bisexual people, and young minority ethnic men. The research is small scale, qualitative and of an introductory nature. Within these parameters it identifies the particular exclusion, inequalities and discriminations experienced by these groups. It records and celebrates the struggles for change, for recognition and for self-determination by these different groups.

The research establishes:

- The importance of a focus on identity within equality strategies. Identity is found to be important in people's positive sense of self, as a basis for people to organise and seek change, and as having practical implications for institutional policy and practice.
- The complexity and fluidity of identity. People construct their identity from more than one source. Multiple identity groupings have specific experiences, situations and identities that need to be addressed within equality strategies.
- The need for new solidarities across and between the different groups that

CONTENTS

1. Introduction	1
Katherine Zappone	
2. Disabled Minority Ethnic People in Ireland: The Need for Recognition	7
Maria Pierce	
3. Black and Minority Ethnic Women: Understanding Identity, Access and Equality in the Health Service	25
Heidi Safia Mirza and Ann-Marie Sheridan	
4. It's Not Just About Ramps and Braille: Disability and Sexual Orientation	49
Michael Brothers	
5. Situation, Experience and Identity of Disabled Women in Northern Ireland	69
Norrie Breslin	
6. Learning to Grow Up: Young Lesbians, Gay and Bisexual People in Northern Ireland	89
Christine Loudes	
7. Young Ethnic Minority Men in Britain	113
Colin Hann	
8. Conclusion: The Challenge of Diversity	131
Katherine Zappone	
Contributors	153
Contact details	155

1 INTRODUCTION

Katherine E. Zappone

1.1 BACKGROUND

The Joint Equality and Human Rights Forum was established to provide an opportunity for members to share ideas and expertise, to engage in joint work and to contribute to wider equality and human rights discussions at British-Irish and European Union level.

Members of the Forum include the Equality Authority, Ireland (EA), the Equality Commission for Northern Ireland (ECNI), the Human Rights Commission, Ireland (HRC), the Northern Ireland Human Rights Commission (NIHRC), the Commission for Racial Equality, Great Britain (CRE), the Disability Rights Commission, Great Britain (DRC) and the Equal Opportunities Commission, Great Britain (EOC).

As one of its first co-operative ventures, the Forum commissioned this joint research project to explore the reality of diversity in peoples' identities. The notion of 'diversity' in recent times has become a core principle in the work of equality and human rights bodies. People are different from one another by virtue of their gender, age, sexual orientation, cultural and ethnic background, religious belief, impairment(s) and other factors. People are part of social groupings such as 'young people' or 'older people' according to such differences. People with different identities often face different equality and human rights issues. Recognising different identities is a critical step in developing policies and practices that create more equal societies and that accommodate differences in the provision of services and in the workplace. An adequate understanding of the diversity of people's identities is therefore necessary to the work of promoting equality and human rights.

1.2 'MULTIPLE IDENTITIES' AS THE RESEARCH FOCUS

Awareness is growing that people's identities are complex. An individual's identity is made up of several factors such as gender, ethnicity and sexual orientation. There are young gay men and disabled older women. There are white men and minority ethnic women. People can often find themselves categorised according to more than one social grouping. Multiple characteristics and membership of more than one social group structure the unique experiences and identity of individuals. This is what is meant by the term 'multiple identities'.

The other side of this is that people can, and often do, experience multiple barriers to equality such as those faced by a disabled gay man or an African-Caribbean woman. Policies for service provision and organisation of work practices have often not been designed to take account of these multiple differences, resulting in exclusion and compounded or multiple discrimination. Consequently a more adequate understanding of people's multiple identities would be of benefit to anti-discrimination, equality and human rights work. There has been little systematic research to date that documents the multiple identities of people in Northern Ireland, the Republic of Ireland and Great Britain. Members of the Joint Forum commissioned this research project as a way to develop knowledge in this area.

1.3 RESEARCH OBJECTIVE

The overall research objective was to explore the experiences of people who fall within a common ‘multiple identity’ grouping and to draw out implications of this for equality and human rights work. The research gave visibility to a number of ‘multiple identity’ groups that had received little recognition to date within the different jurisdictions. The expectation was that results would raise new issues, and increase understanding of how affirmation of difference impacts on the promotion of equality and the protection of human rights. This joint task was challenging due to the complexity of human identity as viewed through the lens of diversity. Simultaneously it was an exciting project, as it explored the experiences and identities of individuals who have remained largely invisible and have been unheard up to now. In addition, it was anticipated that the project would produce useful results, which would contribute to improving the situation of people falling within the multiple identity groupings and identify broader implications for equality and human rights thinking and practice.

1.4 RESEARCH METHODOLOGIES

As indicated this was a joint research project. Members of the Forum undertook to produce a separate piece of research following a common template or approach.¹ Their first task was to identify the ‘multiple identity’ grouping that would be examined. These included: Black and minority ethnic women in Britain (EOC), Black and minority ethnic people with disabilities in Ireland (EA), disabled women in Northern Ireland (ECNI), young gay, lesbian and bisexual people in Northern Ireland (NIHRC), young minority ethnic men in Britain (CRE), and lesbian, gay and bisexual disabled people in Britain (DRC).

The common approach for each piece of research focused on exploring the situation, experience and identity of the chosen group. Each contribution comprised of a literature review, analysis of existing statistical data, and primary research on the experiences of people holding multiple identities. Literature reviews were wide-ranging, drawing on resources within and outside of jurisdictions of forum members. All reviews outlined research about the groups under study as well as issues related to the wider debate on multiple identities. Statistical data was not always available on the chosen groups. Where it was available data indicated the greater disadvantage experienced by people who fall within two social groupings. Primary research focused on investigating how individuals holding multiple identities understand their identities and sense of belonging to different social groupings. It also examined their experiences of accessing health services, namely health and participating in employment. Representatives of equality and human rights organisations as well as service providers in the health sector were also consulted.

Although it was intended to adopt a focus group interview method for each research piece, sometimes this did not prove possible or appropriate. In some cases it was not

possible because of accessibility issues. In other cases there were no obvious 'focus groupings' because there were no organisations representing the particular group under study. Methodologies varied, then, and included one-to-one interviews, case studies, oral narratives and telephone interviews as well as focus groups. Several researchers engaged facilitators known to participants in order to take account of issues of trust and confidentiality. Within most of the research studies, individuals or groups were met in several geographical sites throughout the jurisdiction.

Because the primary research was exploratory in nature, it was small in scale and tightly focused for each 'multiple identity' grouping. However, the overall joint project investigating the issue of multiple identities could be viewed as more significant in scale. A total of 14 focus groups including 105 individuals were held, along with one-to-one interviews of 12 individuals and 3 in-depth case studies. Thirty health service providers and equality experts were also interviewed.

The research project was guided by a co-ordinator whose task it was to develop the template, to offer guidance to researchers, to analyse common themes and identify implications emerging from the research, to edit the collective report² and to encourage a shared sense of the project's ownership. Researchers and research managers met three times throughout the project in order to ensure a cohesiveness of approach, and to discuss any conceptual and methodological issues emerging throughout the research. The initial meeting provided an opportunity to discuss and garner acceptance of the common approach and template. The second meeting focused on a consideration of issues emerging as the research was in progress. At the concluding meeting, researchers and research managers gathered for a daylong seminar to consider their results, and to recommend amendments to the draft concluding chapter written by the research co-ordinator. Every effort was made to make this a mutual endeavor and the meetings were a critical ingredient, even though it meant significant travel for a number of people.

1.5 RESEARCH FINDINGS

The following chapters present the situation and experiences of groups of people who share a common 'multiple identity', as researched by different members of the Joint Forum. As previously indicated individual studies were small in scale and exploratory in nature. Consequently the findings presented do not claim to be representative of a particular population in a certain jurisdiction. This was not the research intent. Rather the findings outline many of the identity issues, discriminatory experiences and unique barriers to equality that these groups of people deal with in their day-to-day lives.

The research tells their stories in very direct and powerful ways. Some of the narratives centre on people's struggle to answer the questions, who am I? To what groups do I belong? The process of self-definition often incorporates a resistance to stereotypes, labels or a sense of being named as 'other'. Individuals discuss how racism, homophobia or disablism impacts negatively on their identity and self-esteem. Their

‘multiple identities’ often mean that they experience significant exclusion and marginalisation especially as they face multiple barriers in accessing basic public services and employment opportunities.

Researchers sketch pictures that help concretise the meaning of multiple identities, and draw out the implications of this for equality and human rights work. The research documents many of the ways in which people face particular barriers to equal access or participation because of the intersection of two aspects of identity. As researchers point out, there are often ‘blind spots’ in mainstream policy when it comes to considering people with multiple identities. Recommendations are made to begin to change these situations.

The concluding chapter draws together common themes that surface throughout the presentation of research on these disparate groups. It attempts to unpack the theory of multiple identities by way of highlighting key findings from the individual studies. It summarises central elements of how people with multiple identities experience treatment by or interaction with health services. It concludes by outlining implications of this research for equality and human rights work.

NOTES

- 1 The development of the template was influenced by an earlier piece of research by Katherine Zappone, *Charting the Equality Agenda*, that developed a framework for an integrated approach to the multi-ground equality agendas of the Equality Authority in the Republic of Ireland and the Equality Commission in Northern Ireland.
- 2 In addition to this collective report a number of members of the Joint Forum plan to publish detailed reports of their individual projects.

2 DISABLED MINORITY ETHNIC PEOPLE IN IRELAND: THE NEED FOR RECOGNITION

Maria Pierce

2.1 INTRODUCTION

Ireland is a multi-ethnic society. Minority ethnic communities include the Traveller community, an indigenous minority ethnic community with a distinct culture and history of nomadism, and one of the largest minority ethnic communities in Ireland. In recent years, Ireland's ethnic landscape has been substantially changed with the arrival of new communities of migrants, asylum seekers and refugees. They come from a multiplicity of ethnic backgrounds. The wide range of countries from which these groups originate gives some indication of the complexity of ethnic diversity of the newly emerging communities. A major feature of Ireland's ethnic communities is that the situation is not static. It is rapidly changing and evolving, especially with respect to the newly emerging minority ethnic communities, which give Ireland its distinctive ethnic mix.

Despite Ireland being a multi-ethnic society, the situation of disabled minority ethnic people in Ireland has not received attention up to now. This chapter outlines some factors that can contribute to this invisibility. These include the segregation of disabled people in Irish society generally, the tendency in Irish society to think of Irish people and groups in universal terms, the exclusion and minority status of people with multiple identities within minority groups and community and voluntary organisations as well as the invisibility of disabled minority ethnic people in statistics.

The chapter highlights the key themes that arose from one-to-one in-depth interviews with nine disabled minority ethnic people in Ireland exploring issues of identity, situation and experience. One key theme to emerge from the study was that disabled minority ethnic people are characterised by heterogeneity. Disabled minority ethnic people differ in terms of type of impairment, history of impairment and impact of impairment on daily living. They differ in terms of ethnic diversity and other diversities such as gender, age and sexual orientation. A second key theme is around commonalities and differences with respect to experience. Disabled minority ethnic people share experiences in common with the wider population of disabled people. For example, they face similar barriers to participation in mainstream society. However, they can also experience disablist barriers and attitudes within their own communities. Disabled minority ethnic people can face a double disadvantage because the cultural differences between disabled people may be ignored. In addition, they may face the same racist prejudices and discrimination as other members of minority ethnic communities. A third theme discussed is the complexity of identity for people with a multiple identity. The contradictions for people holding a multiple identity and the tensions and difficulties that can arise between and within groups are examined. In the final section, some implications of these issues for health services and employment are raised. The themes and issues contained in this chapter are discussed in more detail in a separate report to the Equality Authority (Pierce, 2003, forthcoming).

2.2 INVISIBILITY OF DISABLED MINORITY ETHNIC PEOPLE

There are a number of factors that may contribute to the invisibility of disabled people from minority ethnic groups. The invisibility of disabled people is likely to be a reflection of the segregation of disabled people in Ireland. Disabled people are, and historically have been, faced with exclusion, marginalisation and segregation within Irish society. Segregation and exclusion have, for example, been described as 'the most characteristic and persistent features of educational provision for disabled pupils in Ireland since the nineteenth century' (McDonnell, 2003: 28). Exclusion, marginalisation and segregation affects disabled people from minority ethnic backgrounds, as well as those from the majority ethnic population. As one participant pointed out, you don't often see or meet other disabled people in public. She wondered where were the Irish disabled people.

Conceptual frameworks can contribute to the invisibility of disabled minority ethnic people. The medical model of disability places an emphasis on individual impairments and classification systems. The impairment and not the individual is the focus of attention. This means, as McDonagh (2002) argues, that disabled people are not automatically given the right to be seen as individuals with different genders and histories. Similarly, disabled people are not given the right to be seen as individuals from different ethnic backgrounds. The social model of disability emphasises the way in which the lives of disabled people are limited by prevailing social, cultural, and economic constraints. This approach concentrates on how society disables people who have impairments. However, it can mean that disabled people are presented as a homogeneous group and that ethnic and other differences are ignored (Fawcett, 2000). In Ireland there is a tendency to focus on disability as a unitary category and to consider ethnicity and disability in isolation from each other (Pierce, 2003). This can lead to the marginalisation of minority ethnic people with disabilities.

Disabled minority ethnic people face particular problems of invisibility. For example, there is a tendency in society to portray all asylum seekers and refugees as able-bodied (Roberts, 2000). The failure to recognise that there are disabled asylum seekers and refugees and disabled people among other minority ethnic communities means that these individuals are rendered invisible.

Many voluntary and community groups have little experience of working with new minority ethnic communities (Faughnan and O'Donovan, 2002). It would seem that this observation could be extended to community and voluntary organisations working specifically in the area of disability. Some, but not all, participants were in contact with such organisations and found the support invaluable. However, their engagement with these organisations was always as service users and those from new minority ethnic communities were less likely to have any contact with these organisations.

Organisations of people with disabilities in Ireland are open to involving individuals from diverse backgrounds, despite concerns around resource and other constraints. However, disabled minority ethnic people can be under-represented in these organisations. Most

of the participants in the study expressed a desire to be involved in such organisations. This was not only expressed in terms of an opportunity to add their views and experiences to disability debates but also as a means of making a very real contribution to Irish society. However, many of the participants in the study were unaware of the existence of, or how to get in contact with, organisations of people with disabilities. A typical response was as follows:

'I don't really know any. I never heard of them. What are they? I wouldn't mind knowing more about that.'

The lack of knowledge and information about the existence of such organisations was a major factor preventing them from participating in this way.

In addition to under-representation in disability organisations, disabled people can be an almost invisible sub-group within minority ethnic organisations in Ireland. Indigenous minority ethnic communities, asylum seekers and refugee communities as well as organisations promoting the rights of minority ethnic groups often fail to consider disabled people. This may be because they constitute a minority of individuals within a minority grouping. In addition, little or no information is available about these individuals. Furthermore, minority ethnic communities may be focusing their attention on issues and concerns that essentially affect the majority of the minority population. In this way, matters facing minority groups such as disabled people within their communities may be designated as secondary or non-priority issues.

As yet, there are no existing associations of disabled minority ethnic people in Ireland. This contrasts with the situation in the UK, where such groups have made a very real contribution to the situation of disabled minority ethnic people (Drake, 1999). Many of the participants in the study expressed a strong desire to meet with other disabled people and to be in contact with and involved in disability organisations:

'I would love that. I would find more information. I would see the problems with other people. I feel rejected sometimes. Because they give you disability allowance and that's it. I feel completely like somebody that nobody wants. It is a need for people to socialise together, especially people with disabilities to talk between themselves, rather than feel completely isolated. Generally for people with disabilities to share their experience and overcome the isolation.'

The invisibility of disabled minority ethnic people is exacerbated by the lack of information. For example, the lack of data makes it difficult to statistically identify this multiple identity group and measure inequalities related to this group (Pierce, 2003 forthcoming). This makes it difficult to be specific about the situation of this group in terms of employment, education status, health status and so on. As such it is difficult for policy makers and service providers to identify the needs of disabled minority ethnic people and the extra difficulties they face.

The invisibility of and lack of information about disabled minority ethnic people in Irish society posed some difficulties for the research study. An immediate concern was around difficulties of making contact with potential participants given that there are no existing groups of disabled minority ethnic people and in light of the marginal position of these individuals in disability organisations and minority ethnic organisations. Following contact with disabled people from diverse minority ethnic communities in Ireland, nine one-to-one interviews were carried out. The chapter discusses the major themes that arose during the interviews. Inevitably given the small scale and qualitative nature of the research, the findings cannot be categoric but are indicative of key issues.

2.3 HETEROGENEITY AMONGST DISABLED MINORITY ETHNIC PEOPLE

One of the key issues to emerge from the research is that disabled minority ethnic people are not a single homogenous group. They are characterised by heterogeneity. They comprise people with different types of impairments. The participants in the study had physical impairments, mild learning difficulties and hearing impairments as well as disabilities arising out of chronic illness or as a result of longstanding health problems. Some of the participants had more than one type of impairment. This reflects the different situations of the wider population of disabled people in Ireland. As with the wider population of disabled people, some minority ethnic people have congenital disabilities, whereas others acquired a disability as a child or later in life as an adult. For example, one participant in the study was born with a hearing impairment. Others had acquired a disability due to a disease, illness or as a result of an accident. Some disabled people within Ireland's newly emerging minority ethnic communities are asylum seekers or refugees. For some of these individuals, impairments may have arisen out of war, conflict or torture, as was the case for some of the study participants.

Disabled minority ethnic people differ with respect to whether and how much impairment, and the failure of society to make adjustments to accommodate this diversity, impinges on their daily lives. For some participants, impairment has little or no impact on daily living. For others, impairment presents them with ongoing difficulties on a day-to-day basis. This is especially the case for those with a progressive and degenerative illness. One participant put it in the following terms:

'It is very difficult to live everyday, just waiting. You can't do that much you know. You can't be active. It is affecting your body. Even housework or anything is difficult.'

Disabled minority ethnic people differ with respect to their ethnic backgrounds. Ireland has a history of multi-ethnicity. In recent years, there is a growing appreciation of Ireland's multi-ethnic make-up. Yet, traditionally, there has been a tendency to portray Ireland as an ethnically homogeneous society (Fanning, 2002). Minority ethnic communities in Ireland are diverse and rapidly changing. Disabled minority ethnic people too come from diverse ethnic backgrounds. Participants in the study included Travelling people:

'I am an Irish Travelling person. I was born in Ireland. Both my parents are Irish Travelling People.'

Participants included individuals of mixed race origin, from Central European countries and from a range of African countries. Participants included individuals born in Ireland, and others who had arrived as asylum seekers or refugees.

Disability and ethnicity are important factors structuring their experience. However, disabled minority ethnic people hold multiple identities and disability and a wide range of factors structured the experiences of participants in the study. Factors of importance raised by participants included gender, age, sexual orientation and religion. Other significant factors included issues of citizenship status, employment status and occupation as well as issues related to family status.

2.4 EXPERIENCES: COMMONALITIES AND DIFFERENCES

Despite the heterogeneity of minority ethnic people with disabilities, there are commonalities, as well as differences, between people positioned in this social grouping. As disabled people, disabled people from minority ethnic communities share common experiences with disabled people among the majority ethnic population in Ireland. Within the wider Irish society, disabled people from all ethnic backgrounds (majority and minority) face discrimination on the basis of disability. Participants in the study referred to low expectations of and for disabled people and lack of encouragement and opportunities for disabled people to participate fully in the social, economic, political and cultural spheres of life within the dominant culture. Participants in the study found themselves isolated and marginalized by such things as inaccessible buildings, inadequate transport, inflexible or rigid services and practices, unsuitable housing and lack of aids and equipment.

'I was thinking about doing a [training] course. What was stopping me the whole time was that they have no lift and there's an upstairs. They are moving. They are building a new centre with a lift.'

Some participants spoke about feeling a sense of loneliness, isolation and exclusion. This is, in part, a result of their experiences of living in residential homes for disabled people or being confined to the house or of the lack of opportunities to socialise with their peers. One participant spoke about her experiences of a social club for disabled people.

'Mainly we go on little outings and trips. Dinner parties and Christmas parties. There were a lot of older people. If there had been more my own age group ... I was only 21 at the time or 20, they were all in their 40s. I still went.'

Isolation and segregation are also encountered by disabled people in the wider population.

At the same time, the experiences of disabled people from minority ethnic communities differ in other ways from disabled people in the wider population. Disabled minority ethnic people are faced with the fact that mainstream society does not always take account of cultural differences between people with disabilities. Disabled minority ethnic people often had to make sense of and find their way through a society imbued with different customs, norms and practices to those in minority ethnic communities or other countries. For example, a Deaf participant explained that in Ireland it was widely expected that all people including Deaf people would communicate orally. This had not been the case in his country of origin. There, Deaf people communicated with each other and the hearing population through sign language. After coming to Ireland, he had been compelled to learn to lip-read.

Having being brought up and socialised within minority ethnic communities in Ireland or in a different country with different values, customs and practices around disability, some participants spoke about feelings of isolation, rejection and confusion when they came into contact with the dominant culture in Ireland. In particular, participants expressed concern that they did not often meet or see other disabled people in Ireland. Participants felt that there was little awareness of the needs of disabled people and that disabled people were not readily accommodated by services. In addition, some participants felt that Irish people showed little knowledge or understanding of disabled Black and minority ethnic people.

Disabled minority ethnic people face disablism within their own communities. Negative perceptions of disability within the dominant culture are manifest in minority ethnic communities as well. Disablist barriers within minority ethnic communities are a factor preventing disabled people in their communities from participating fully in society. Parents and extended families can oppose autonomy for minority ethnic people with disabilities. This may be driven by a concern to protect disabled people, especially if they have a congenital or severe disability.

'I'm planning on doing an independent living course in Dublin ... They didn't want me doing that either. They think you should stay with your own mother and father ... They put all that pressure on you. My sisters keep saying to me that you should try and do these things. It's the older people. They say 'Are you sure you should be doing this?' ... that kind of thing. It's because of my disability. They completely smother you. [Minority ethnic people] with a disability definitely need more independence.'

Unlike disabled people in the wider population, the experience of disabled minority ethnic people can be structured by racism, which can be both direct and at an individual and an institutional level. Disabled minority ethnic people experience racism in common with other members of minority ethnic communities. Historically and

contemporarily, there is evidence of racism in Ireland towards Travellers as well as other minority ethnic communities (Crowley, 1999; FAQs Research, 2001; Fanning, 2002). Disabled Travellers and other disabled minority ethnic people are subjected to the same experience of racism. Some, but not all, participants in the study, including Travellers, asylum seekers and refugees as well as Black Irish people, reported occasional instances of overt racism.

'They didn't like the colour that I have. They started calling me names. It was a few young fellas. It made me feel hurt. It made me feel terrible.'

Disabled asylum seekers and refugees may experience distinct difficulties. Asylum seeker participants spoke about the difficulties of living in hostel accommodation such as lack of privacy. One participant spoke about the discrimination he faced in his hostel accommodation because of his disability. Disabled asylum seekers and refugees can also face separation from other family members. One participant explained:

'There are things I can't do on my own. The fact that there are not here, it makes me sick. My children, I miss them. So, in fact, the whole family is not here. It would be much better if they were here.'

2.5 COMPLEXITY OF IDENTITY

People draw their sense of identity from a range of sources. The concept of multiple identity is a useful concept for reflecting the complexity of people's social identity (Fraser, 2000). Disabled minority ethnic people hold a variety of identities based on ethnicity and disability as well as gender, age, religion, sexual orientation and so on. It highlights differences between people within groups as well as differences between groups. Some concern has been expressed about using the concept of multiple identity. For example, it has been argued that people must be seen as 'holistic individuals' and that the notion of multiple identities can lead to a process of fragmentation. The concern is that disabled minority ethnic people, for example, would simply be seen as a product of what it is like to be disabled and what it is like to be from an ethnic minority community. However, Taylor (1998) argues that a person can develop a unified sense of self even though they have more than one identity.

Each of the identities that people hold is complex. For example, Modood (1997) and Shakespeare (1996) comment on the complexity of ethnic identity and disability identity, respectively. The complexity of disability identity was reinforced in this study, which found that there were differences among disabled minority ethnic people in Ireland with respect to the extent to which they identify as disabled people, if at all. Some participants in the study readily claimed that they had a disability, whereas, others explained that they did not identify as disabled people and strongly rejected impairment in the construction of their identity.

'I don't see myself as a person with a disability. It's only the other person who sees me as that ... I want to be myself, despite my disability.'

Despite differences in disability identity, all of the participants strongly emphasised abilities and that they were active individuals, doing as much as they could.

'I am in a wheelchair and have a disability and can't get out much. I still can get out. I still wouldn't let that stop me. Well, I do all that I can for myself. I do the shopping and do everything really I can do.'

People do not necessarily attach equal weight to the identities that they hold. For some people, one identity can feature more strongly than another identity or other identities. For example, one participant explained that his identity with Deaf culture was more important to him than ethnic identity. Another participant considered religion to be the most important component of his identity and more important than disability or ethnicity.

'Religion is very, very important to me as a person ... At the moment, religion is the most important part of my identity. That is the area I am most involved in.'

For others, a number of aspects of their identity can feature significantly at the same time. For example, one participant spoke about being disabled, a woman, a mother, a wife and from a minority ethnic community. Another participant explained that describing himself and his experiences in terms of disability and ethnicity was problematic, as he held a gay identity, which was an important aspect of his identity and gave him a sense of who he was.

Identities are not fixed. They are changeable and shifting. At any one time, a person may hold multiple identities, but choose to assert or express an identity that is most meaningful to them at that time or in a particular context. For example, one participant in the study expressed her ethnic identity through her participation in an African Choir. This does not mean that ethnic identity is the totality of her identity. Her identity as a woman, a disabled person, a parent and a woman living in poverty were also important components of her identity.

2.6 MULTIPLE IDENTITY: THE CONTRADICTIONS

Having multiple identities allows a person to relate to different people in different situations and contexts in different ways at different times. It also means that their social relations can be multi-faceted and imbued with contradictions. This has implications for identity. Certain social interactions can reinforce a positive sense of identity, while simultaneously, other social interactions can undermine a person's sense of identity. This can be illustrated from the position of a disabled minority ethnic person. A disabled minority ethnic person may express their ethnic identity by

participating in shared cultural, linguistic and religious traditions of an ethnic group. Williams (1996) refers to this expression of collective identity as *diversity*.

At the same time, disabled minority ethnic people live within the structures of the wider society. This may mean that they may experience marginalisation or discrimination within the dominant culture on the basis of their ethnicity. A person's sense of self identity can be distorted or injured if the group to which one belongs is either devalued by the dominant culture, or is rendered invisible or subjected to disrespect. The devaluing of a group can have the effect of enforcing a negative identity on people.

There appears to be a strong desire among people with multiple identities to be able to determine their own identity. This was the case, even where an identity or identities that a person holds were at odds with the values of the dominant group or culture. It seems that people are highly attuned to the fact that an identity or identities they hold may be devalued or disrespected by the dominant group or culture.

Difference from the dominant ethnic group may act as the basis for resistance against marginalisation or discrimination in alliance with other members of the minority ethnic group. Williams (1996) suggests that individuals can hold multiple identities but to claim difference it is necessary for people to temporarily freeze differences in their identities. Collective resistance may result in a rejection of enforced negative attributes and a positive revaluing of identities. This can be exemplified by the struggle for recognition by the Traveller community, which is still not widely accepted as an indigenous minority ethnic group in Ireland. The struggle for recognition by Traveller people coincides with a growing consciousness of Traveller identity and rights and there is growing acceptance that Travellers have their own identity and culture.

Not all disabled minority ethnic people have the opportunity to express their ethnic identity. There were some participants in the study who had no contact with other Black people or members of their minority ethnic group. They spoke about a sense of isolation that resulted:

'I'm a Traveller person ... I feel like some part of my life is missing because I am not meeting with Traveller people. I feel like a bit of an outsider. I can get lonely and depressed about it.'

The values of the ethnic group towards disabled people may constitute a form of oppression or discrimination and create a division within the group. For people with multiple identities, this may lead to a sense of ambivalence about an identity. One participant put it in the following terms:

'Sometimes it is important. Sometimes it can be a bit of a pain ... It's hard. It's so traditional. Do you know, there is only one set of rules and they apply to everyone ... Everything would be affected. It was. ... It wasn't really expected of you to go to school. Girls were just really prepared for getting married from a young age, do y' know. That

was it. That was all that you were able to do. Being a person in a wheelchair, it's definitely not expected of you to do anything.'

This ambivalence suggests that people with multiple identities can experience a cross-pull with respect to various affiliations. As Vernon (1999) argues, people with multiple identities can enter into shared alliances with some groups, while at the same time contesting the dominant discourses of the group. This is exemplified in the study by the experience of a Deaf participant who was involved with the Deaf community. In alliance with the Deaf community, he was active in challenging prejudice and discrimination against Deaf people and promoting non-discriminatory forms of education and services for Deaf people. At the same time, he was active in challenging the Deaf community and clubs in Ireland to recognise diversity and to tackle racism among Deaf people and organisations.

Claiming all of one's identities appears to be important to participants, and something that people are not willing to forfeit easily. However, this can lead to difficulties and tensions, especially where the group considers an identity to be incompatible with the values of the dominant group. These tensions and difficulties are played out both within minority groups and within the wider society. In either case, resistance by people to demeaning stereotyping, prejudice and discrimination can be a difficult and painful process. People with multiple identities are faced with making difficult decisions and employing different strategies to cope with this scenario. One participant in the study who felt that his chosen religion would be incompatible with the values of his ethnic group made a conscious decision to dissociate himself from the group so that his religious identity would not be undermined. Another participant described the very painful experience of separation and isolation from his community following the disclosure to members of his ethnic group that he was a gay man. In addition to withdrawal from certain situations, another strategy adopted was to suppress or decide not to disclose one's identity in certain situations. For example, based on past experiences of discrimination, a strategy adopted by one participant was to suppress his identity in seeking employment as well as in the workplace. Dissociating from groups or suppressing identity can present their own difficulties, as issues of difference and subordination are not resolved.

2.7 IMPLICATIONS FOR SERVICE PROVISION AND EMPLOYMENT STRATEGIES

People in Irish society have traditionally been considered to be a homogeneous group of people. This way of thinking is reflected and reproduced in all Irish institutions, including in health and disability services as well as in the workplace. Institutional discrimination can be said to exist where things are done in a way which assumes that all clients are from the same background as the majority population (Baxter, 1995). Following this argument, the assumption can be made that it is the norm for people to be 'able-bodied' and from the same ethnic, cultural and linguistic background as the rest of the white majority Irish population. As one participant explained:

'Many Irish people have never seen a Deaf Black person before.'

Just as in the wider society, disabled minority ethnic people can be rendered invisible or viewed as 'atypical' both as users and providers in health and disability services. There needs to be awareness in health and disability services of the cultural norms and values that inform organisational structures and practice and the potential of these to reflect prejudice can be important.

In common with all disabled people, disabled minority ethnic people face barriers to participating in many areas of Irish society. In a similar way, they face common barriers to accessing health and disabilities services. Examples from the study include difficulties that participants experienced in accessing disability aids and equipment from health boards or feelings of anxiety and concern as a result of waiting prolonged periods for a response or treatment from health services. Similarly to Irish Deaf people, Deaf people from minority ethnic communities face a lack of sign language interpreters when using health and other services. Such experiences for disabled people from majority ethnic and minority ethnic communities can lead to exclusion and discrimination and needs to be addressed by health and disability services.

Disabled people are not a single unitary group of people. Ethnicity is one way in which disabled people differ. This has implications for health and disability services. A lack of understanding of the cultural beliefs, practices and needs of disabled minority ethnic people or a failure to respond effectively to disabled minority ethnic people can result in the provision of culturally incompetent health and disability services. Lack of knowledge and information about health and disability services as well as language and communication differences were examples from the study of barriers preventing disabled minority ethnic people from accessing health and disability services. One participant suggested that:

'There should be more awareness of people with disabilities. An information centre for asylum seekers and refugees with disabilities, to know where they should go to and perhaps an information pack.'

The problem of direct or overt racism as encountered by disabled minority ethnic people in Irish society was raised earlier. Racism can also be reflected in institutions such as health and disability services. Institutional racism is considered to be a major factor preventing disabled minority ethnic people disabilities from accessing services (Vernon, 1998; Shah and Priestley, 2001) and can lead to isolation and exclusion. Institutional racism experienced by disabled minority ethnic people and their families trying to access health and disability services can take subtle and distinctive forms. For example, a health service worker pointed out that Traveller families may face particular obstacles to accessing residential or respite care for disabled children because of stereotypical views of Traveller behaviour or discriminatory practices that have grown up within organisations. Disabled people from newly emerging minority ethnic groups may too be confronted with similar racist practices and behaviour when attempting to access health

and disability services. Health and disability services need to acknowledge the potential for institutional racism, both historically and contemporarily, and to develop the capacity to prevent and address any racist practices and prejudices among staff in their organisations.

Disabled minority ethnic people, as noted above, also experience disabilism across Irish society. This has a particular relevance in services, including health services, targeting minority ethnic groups. It is important that such services have a capacity to include and benefit minority ethnic people with disabilities.

People may be categorised as disabled minority ethnic people, because of differences of ethnicity and disability. However, it is important for health and disability service providers to recognise that there are differences within groups and that people hold multiple identities. For example, the identities of disabled asylum seekers and refugees encompass not only ethnicity and disability, but also those of asylum seekers and refugees. Acknowledging this makes it easier to understand that some disabled minority ethnic people may be reluctant to approach health and disability services because of uncertainty about their citizenship status or that they face added difficulties due to separation from their families. Others may have acquired a disability arising out of war, conflict or torture. This may affect the way that they use health and disability services. For example, they may be reluctant to approach such services due to fear, suspicion or distrust based on past experiences in another country. It is equally important that health and disability service providers recognise that people also have different histories and that they differ according to other criteria such as gender, age, sexual orientation, religion and citizenship status, some of which may be more significant than ethnicity or disability.

The absence of ethnic groups and disabled people from health data monitoring systems in Ireland has been noted (Pierce, 2003, forthcoming). The regular gathering of data relating to ethnicity and disability within health services would make it easier to plan and monitor health services for minority ethnic people, disabled people, and minority ethnic people with disabilities. However, in some circumstances disabled minority ethnic people may choose not to disclose certain aspects of their identity. A decision not to disclose ethnicity or impairment could be respected by ensuring that principles of self-identification and choice are hallmarks of all health and disability data collection systems.

As noted above, disabled minority ethnic people can face particular barriers when accessing health and disability services. The representation of disabled minority ethnic people or at least the concerns of disabled minority ethnic people may go some way to addressing these barriers. For example, advocates from the community and voluntary sector could play an important role in articulating and representing the concerns, views and contributions of disabled minority ethnic people in relation to health and disability services. In a similar way, groups and organisations representing minority ethnic groups

could take account of issues facing disabled people from their communities when promoting minority group rights. Equally, groups and organisations representing people with disabilities could take account of issues facing minority ethnic people with disabilities.

The marginalisation of disabled people in Irish society is reflected in their low level of participation in the labour market. Barriers to participation include a failure to accommodate physical and other impairments and chronic illness, low expectations of disabled people, poor educational qualifications and physical barriers to participation. For disabled minority ethnic people, there may be additional barriers such as language barriers and exclusion from social networks. Unemployed people with multiple identities may face multiple barriers to accessing employment and specific employment support initiatives may need to be put in place to improve their opportunities to participate in employment. Racism and disablism is reflected in the workplace, such that disabled people from minority ethnic communities may potentially face discrimination from employers on two fronts, that is ethnicity and disability. A range of obstacles, including but not exclusive to issues related to ethnicity and disability, might be at play to prevent disabled people from minority ethnic communities from getting a job. From the point of view of the individual, it is not always easy to discern the significance of any one obstacle, when there are a range of interplaying factors. One participant put it in the following terms.

'I'm sure it's just because there is no job around, but that is why I have not been able to get a job.'

'I can't actually put that down to my race anyway... in my CV, can easily see that I'm Black or a foreigner or that...because of my name, they know that I am not Irish. They can look at the secondary school that I went to and then they ... that is the feeling that I am having. I cannot say for sure that that is the reason.'

'I don't state in my CV that I have a disability. I know that would definitely scare them away from asking me to come for an interview. They might feel I would be like a liability and I might not be able to cope or work. I don't state that.'

This is in spite of equality legislation in the area of employment. Equality practices in enterprises aimed at preventing discrimination and promoting equality across all nine equality grounds in the recruitment of employees as well as in the workplace are crucial for achieving equality for disabled minority ethnic people in the area of employment. In addition, employers may need to recognise and take account of the fact that employees or potential employees may differ on more than one equality ground.

2.8 CONCLUSION

Disabled minority ethnic people are individuals with different histories, impairments, ethnic backgrounds, genders, ages, sexual orientations and religions. Disabled minority ethnic people occupy a very marginal position in Irish society. They are by and large invisible. For instance, there is a dearth of information about disabled Travellers, disabled asylum seekers or refugees or disabled people from other minority ethnic communities. There is a lack of awareness, knowledge and understanding of the issues affecting these individuals. The marginal position of disabled minority ethnic people in Irish society mirrors to some extent the marginalised position of disabled people generally and the barriers that prevent disabled people from fully participating in social, economic, political and cultural activities. However, there are other distinctive ways in which disabled people from minority ethnic communities are excluded from Irish society. There is no formal acknowledgement of the existence of disabled minority ethnic people. Disabled minority ethnic people face discrimination not only on the basis of disability but also racist discrimination. They can face barriers preventing them from integrating into Irish society such as lack of access to social networks or language and cultural differences. They occupy a minority position within the disability sector as well as within organisations and groups representing minority ethnic groups. Disabled asylum seekers face the additional problems of non-citizenship status, insecure accommodation and often isolation from family members.

Recently, debates around disability in Ireland have begun to open up to areas such as gender, sexual orientation and ethnicity. Elsewhere, this departure has led to a burgeoning of debate and the inclusion of a greater range of voices with respect to disability (Fawcett, 2000). This is in spite of the concern that focusing on divergent issues and identities in debates about disability would lead to fragmentation. There has been an expression of interest among disabled minority ethnic people participating in this study to meet with other disabled people and to be in contact and involved with disability organisations. In addition, some participants interviewed for the study expressed a desire to meet and share their experiences with other disabled minority ethnic people. There is a growing awareness among community and voluntary organisations to embrace this diversity (Faughnan and O'Donovan, 2002). However, there are barriers preventing disabled minority ethnic people from accessing such organisations. Addressing these barriers would go some way towards the greater inclusion of the views and concerns of and participation by disabled minority ethnic people in Irish society.

Exclusionary and discriminatory practices facing disabled minority ethnic people in the wider Irish society are reflected in health and disability services. Disabled minority ethnic people also face a range of barriers, which results in their exclusion from, and segregation within the labour market or lack of progression within employment. Disablism and racism confronts disabled minority ethnic people in their attempt to access employment as well as in their workplace.

REFERENCES

- Baxter (1995) 'Confronting colour blindness: Developing better services for people with learning difficulties from Black and ethnic minority communities' in Philpot, T. and Ward, L. (eds.) *Values and Visions: Changing Ideas in Services for People with Learning Difficulties*, Butterworth-Heinemann, Oxford, pp. 203-17.
- Crowley, N. (1999) 'Travellers and Social Policy' in Quin, S., Kennedy, P., O'Donnell, A. and Kiely, G. (eds.) *Contemporary Irish Social Policy*, UCD Press, Dublin, pp. 243-63.
- Drake, R. (1999) 'Minority Ethnic Communities and Disability' in Drake, R. (1999) *Understanding Disability Policies*, MacMillan Press, London, pp. 148-62.
- Fanning, B. (2002) *Racism and Social Change in Ireland*, Manchester University Press, Manchester.
- FAQs Research in association with Loyal, S. and Mucahy, A. (2001) *Racism in Ireland: The Views of Black and Ethnic Minorities*, Amnesty International, Dublin.
- Faughnan, P. and O'Donovan, Á. (2002) *A Changing Voluntary Sector: Working with New Minority Communities in 2001*, Social Science Research Centre, UCD, Dublin.
- Fawcett, B. (2000) *Feminist Perspectives on Disability*, Prentice Hall, Harlow.
- Fraser, N. (2000) 'Rethinking Recognition', *New Left Review*, 3 (2000), 107-120.
- McDonagh, R. (2002) 'The web of self-identity: Racism, sexism and disablism' in Lentin, R. and McVeigh, R. (eds.) *Racism and Anti-Racism in Ireland*, Belfast: Beyond the Pale Publications, pp. 129-35.
- McDowell, P. 'Education Policy' in Quin, S. and Redmond, B. (2003) *Disability and Social Policy*, UCD Press, Dublin, pp. 28-44.
- Modood, T. (1997) 'Culture and Identity' in Modood, T. and Berthoud, R. (eds.) *Ethnic Minorities in Britain: Diversity and Disadvantage*, Policy Studies Institute, London.
- Pierce, M. (2003) 'Ethnicity and Disability' in Quin, S. and Redmond, B. *Disability and Social Policy in Ireland*, UCD Press, Dublin, pp. 113-128.
- Pierce, M. (2003, forthcoming) *Issues of Multiple Identities for Black and Minority Ethnic People with Disabilities and their Implications for Service Provision and Employment Strategies*, Equality Authority, Dublin.
- Roberts, K. (2000) 'Lost in the System? Disabled Refugees and Asylum Seekers in Britain', *Disability and Society*, Vol. 15, No. 6, October 1, pp. 943-8.

Shah, S. and Priestly, M. (2001) *Better Services, Better Health: the healthcare experiences of Black and minority ethnic disabled people*, Leeds Involvement Project, Leeds.

Shakespeare, T. (1996) 'Disability, Identity and Difference' in Barnes, C. and Mercer, G. (eds.) *Exploring the Divide: Illness and Disability*, London.

Taylor, D. (1998) 'Social Identity and Social Policy: Engagements with Postmodern', *Journal of Social Policy*, 27, 3, 329-350

Vernon, A. (1998) 'Multiple Oppression and the Disabled People's Movement' in Shakespeare, T. (Ed.) *The Disability Reader: Social Science Perspectives*, Cassell, London, pp. 201-210.

Williams, F. (1996) 'Postmodernism, feminism and the question of difference' in Parton, N. (ed.) *Social Theory, Social Change and Social Work*, Routledge, London, pp. 61-76.

3 BLACK AND MINORITY ETHNIC WOMEN: UNDERSTANDING IDENTITY, ACCESS AND EQUALITY IN THE HEALTH SERVICES

Heidi Safia Mirza and Ann-Marie Sheridan

3.1 THE STUDY

The overall purpose of the study was to explore the experience and identity of black and minority ethnic women¹ in Britain and their access to the health service in the UK. In particular, the study focuses on the complex ways in which a range of black and minority ethnic women, with different life experiences, draw on their specific cultural knowledge and social resources² when encountering the health service. Focusing on the women's multiple identities in the context of their strategies to maintain health and well being enables us to explore the ways in which the specific situations and experiences they encounter, challenge or support the core value of 'equality of access' within the health service in particular, and the equality agenda in general.

A total of forty black and minority ethnic women living in a large multiracial inner city area of London took part in the study. The research provided a 'snap-shot' of the health issues encountered by black and minority ethnic women of different ages, social classes, and from a variety of cultural and religious groups. Data were gathered³ using an adaptation of an 'oral narrative approach' (Vaz, 1997; Rassool, 1997). This enabled the women to "tell their stories" in relation to who they are (identity) and what they experience (access to health and well being).

The research involved three focus groups with thirty-four ethnic minority women who attended a health programme and community groups. The groups, which had eight to fifteen women present in each session, came from a range of different ages, occupations, cultures and religions. We also conducted three case histories of women from a range of identity positions: a British born African professional working mother; a younger single African Caribbean mother and community worker; and a middle-aged Afghani mother, doctor and asylum seeker. Three interviews were undertaken with health professionals, including two black and minority ethnic women. These helped contextualise the issues raised by the women, and to examine their understanding of the equality agenda in the Health Service.

3.2 MULTIPLE IDENTITY AND BLACK AND MINORITY ETHNIC WOMEN

The distinctive demographic characteristics of black and minority ethnic women are often hidden within the broad brush of the Census classifications, which masks the diverse economic, social, cultural and religious differences between and among the 2.3 million black and minority ethnic women living in the UK (WEU, 2002). From the generalised census categories we know that in Britain, South Asian women make up the largest group within the category 'black and minority ethnic women' with 22 per cent of Indian descent, 15 per cent of Pakistani and 6 per cent of Bangladeshi origin. Black Caribbean women make up 13 per cent and Black African 12 per cent. In addition, 12 per cent of black and minority ethnic women are classified as 'Mixed', 6 per cent as 'Other Asian', Chinese women make up 4 per cent, 'Black Other' 2 per cent and 'Other' 8 per cent.⁴

There are few research studies that explore the social and cultural positioning of black and minority ethnic women. Black and minority ethnic women are often invisible occupying a 'blind spot' in mainstream policy and research studies, which talk about women on one hand or ethnic minorities on the other (Mirza, 1997). For example, important differences are overlooked if the women are subsumed under the homogeneous term 'black and minority ethnic women'. This overarching collective term can incorporate recent refugees fleeing war and famine, to third generation Afro-Caribbean settled migrants who have established work and cultural patterns in the UK.

The issues become even more complex when we look further within, to reveal the multiple identities of the various black and minority ethnic women. The women have multiple experiences in terms of age, sexuality, disability, religious and cultural differences. For example, an older Asian widowed woman who has worked in the family business will have a very different identity and face different equality issues compared to a younger professional Somali woman refugee doctor unable to secure employment. Each woman therefore has a different 'story' to tell. Just as their experiences are different, so too multiple definitions of themselves have evolved in terms of their everyday lived experience of gendered and racialised social relations (Brah, 1996; Mirza, 1997).

Universalistic generalisations concerning the majority (white) female population do not hold true for different black and minority ethnic women. For example, all minority ethnic groups contain more children and fewer elderly than the white population. Thus, while child dependency ratios for Bangladeshi women are more than double that of the white population, elderly dependency ratios are 3 times lower for black groups than for white (CRE, 2002). Similarly Pakistani and Bangladeshi women are more likely to have children in their early 20s, be married and not working than white women (Bhavnani, 1994; Dale et al, 2002). In contrast, African Caribbean women are more likely to be employed in skilled manual work and are 3 times more likely to be lone parents than any other group (Owen, 1994; Berthoud, 2001). Thus, the issues faced by different groups of women in terms of caring, working, health and service needs are substantively different. This has implications for equality of access.

3.3 POVERTY, HEALTH AND EXCLUSION

The link between socio-economic position and inequality in health plays an important role in explaining the health experiences of minority ethnic groups, including women (Nazroo, 2002). Patterns of ill health for black and minority ethnic communities in Britain, related to social disadvantage such as poverty, housing, safety and living in insecure situations, are well established (Acheson 1998). Nettleton and Burrows (1998) argue that it is not only the physical effects of such material deprivation which affect health, but also the psycho-social processes associated with the experience of such deprivation.

3.3.1 Poverty and ill-health

The narratives of the women in this study reveal the personal consequence of the interlocking structures of social and economic exclusion. Many of the women tell their 'stories' of becoming ill through feelings of lack of control and disempowerment in relation to faceless bureaucratic public services. The emotional cost of living in unsuitable and unstable living conditions is amplified by isolation and experiences of racial harassment (Chahal and Julienne, 1999).

This is expressed through profound feelings of fear which manifests itself in worry, headaches and stress related illness. Yet the women do not see themselves as victims and talk about the exclusionary processes they encounter in terms of unsafe places and a notion of 'them' (the big 'faceless' council) in relation to 'us' (small 'silenced' tenant), as Muniza explains:

'I am afraid the council will throw me out if I tell them about the problems in the flats... I don't say anything... I am scared to tell them anything... I get headaches and pains in my neck because I worry so much... there's no one to talk to.'
(Muniza, Bangladeshi mother, 30, in U.K. 10 years)

3.3.2 Identity and social exclusion

Not only are black and minority ethnic women's experiences shaped by their immediate living conditions, they are also influenced by the wider social expectations of them as 'good wives' and 'good mothers'.⁵ A recent study of immigrant women's health in Canada suggests women from Asia, Africa, Central and South America and the Middle East define their personal physical health in relation to their ability to function as resources for their families' well-being (Meadows et al, 2001). It would appear that gendered social cultural conventions which link women to the private domestic sphere clearly operate to tie working class, black and minority ethnic women to their role in the home (Mohanty, 1997).

As keepers of the family honour many women are anchored in the patriarchal discourse of 'honour and shame' (Westwood and Bhachu, 1988). Pride in the home, as good home-makers is crucial to 'who they are' as wives, mothers, daughters. Therefore living in cramped, unhygienic unsuitable conditions over which they have no control means that an essential part of who they are as 'women' is negated – this results in constant stress.

[There are] 'too much problems in my home – it's so dirty – I worry all the time about it – it affects my health I can't sleep – for real I can't sleep – I worry all the time.'
(Ilham, Turkish mother, 32, in U.K. 3 years)

It is through Zena's identity as a mother that she expresses her anguish with her home. She is concerned about the children and feels responsible for the safety of the family and the situation they are in. She explains:

'Yesterday when I was depressed I kept thinking – how can I get out of this area – I was crying for many hours – my children were seeing me and that makes it even worse – I can't find a solution.'

(Zena, Afghani mother, refugee and doctor, 34, in U.K. 5 years)

Ironically it is not her material conditions, but her role as a mother which historically brought women like Zena, that is black and migrant women, to the attention of health and social services as 'bad mothers' (CCCS, 1982; Bryan et al, 1985). Their visibility was not about equality of access or help, but because they were seen to pose a problem.

Professionals in the health service like Hazel, a 40 year old African Caribbean woman, acknowledge the relationship between socio-economic conditions, mental health and mothering in their daily working experience. Hazel is an 'outsider within' (Hill Collins, 1998) – that is a black woman with her own 'cultural knowledge' who also works in a mainstream, mainly white run public health service. She is able to draw on her experience and social positioning to understand the social issues she observes in a different way to that established and embedded within the health organisation. She thus grounds her analysis not in familial pathology, but in a way that appreciates the women's struggle and motivation. She acknowledges the political context and consequence of the 'maternal control':

'A lot of black people will say they are concerned about their children's education – it's not an accident that our children are doing badly at school – although it's a real concern you feel kind of paralysed – if the mum's mental state is such that she's not functioning, she's not going to have the resources to deal with it or other issues that may arise'.

(Hazel, African Caribbean mid-wife and mother, 40)

While black and minority ethnic women often defined themselves and others through 'acts of mothering' (Reay, 1998), the lack of childcare generally, and child friendly facilities in the health services in particular, is quite spectacular. Rigid delivery structures and insensitive planning often ensured GP's clinics aimed, in theory, at women as service users actually actively excluded them. Hazel explains how exclusionary practices operate in relation to post-natal checks:

‘Talking about women’s health is often around childcare – I can’t tell you the amount of times I referred women to GPs for their 6 week post natal check up and they won’t go because they have to bring the baby – they weren’t able to leave the baby anywhere – the GP refuses to do a physical examination (with the baby present) ... look at the position the woman has to get on to on the couch – she can’t take the buggy into the surgery because she’s not allowed – she ends up not having her check up... they don’t care – the onus is on the woman to provide her own childcare – I don’t think they (the GP) give a second thought to it.’
(Hazel, African Caribbean mid-wife and mother, 40).

Whatever the needs or identity of the women, the GPs’ surgeries had an identity of their own. As far as the GPs were concerned they delivered a service at a time and for a purpose as they defined it – it was their service – and quite simply up to the women to ‘fit in’. Lack of consideration shown by GPs to women was borne out by Hazel, who said:

‘The times are ridiculous – it [the surgery] doesn’t take into account what’s going on for women – the surgeries happen right at the time when the woman is dropping the children off [at school] and she ends up having to take them with her [to the surgery] – [there’s] no space to get a buggy in the door – there’s no food on site – usually no water – awful receptionists – dirty furniture – it really is ridiculous.’
(Hazel, African Caribbean mid-wife and mother, 40).

3.4 RACIALISATION OF HEALTH

The ‘racialisation of health issues’ refers to the way in which so called ‘objective’ health data and ‘facts’ are actually informed by acknowledged and unacknowledged background racial presumptions (Ahmad, 1996). The consequences of such ‘racialisation’ is that differential treatment for different ethnic (and class) groups is prejudged on the basis of spurious ‘racialised’ scientific knowledge. There is an assumption that populations can only be meaningfully understood if divided into ‘ethnic’ or ‘racial’ groups, which are then taken as primary categories and used for explanatory purposes (Ahmad, 1996; Nazroo, 1998). Thus, variations in the health status of different ethnic communities are all too often “rooted in over simplistic culturalist explanations, which trace differences in health variations to behaviour, which in turn are linked to cultural differences” (Mason, 2000: 92).

3.4.1 The process of stereotyping

The construction of black and minority ethnic communities as ‘other’ has proved significant in understanding the women’s access to health. When a woman enters a doctor’s surgery she is preceded by racial stereotypes. She is often not seen as an individual – she is constructed first and foremost in a gendered racial category: as a ‘subservient Muslim woman’ (Brah, 1996); a ‘single black woman’ (Reynolds, 1997); an ‘undeserving refugee woman’ (Crawley, 2001). Stereotypical, racialised, cultural assumptions about black and minority ethnic women are widely held and reinforced by

the media (Law, 2002). The health professionals were aware of how pervasive this way of thinking is in the health service as Valerie and Jacinta explain:

'I think there are very unsympathetic doctors out there – I think if you come in as the stereotypical image of being single and having children by more than one father and have limited English I think that the service is probably diabolical.'
(Valerie, white NHS Trust Manager, 40)

'We see some black and ethnic minority families having so many children – maybe they have 3 under the age of 5 – we perceive it as a problem... but maybe they don't – it's more natural for them to have larger families... we make assumptions of what is right and wrong.'
(Jacinta, African Caribbean health visitor, 42)

3.4.2 Cultural assumptions

One dimension of the racialisation of health issues is the construction of professional knowledge about black and minority ethnic women. The treatment of many women from different cultural and social backgrounds has often been predetermined by existing 'professional' knowledge about their bodies and minds (Simmonds, 1997). At the core of this discourse of power is the embedded practice of 'knowing the women better than they know themselves' (Mirza, 1997). In our study, most women experienced this gendered racialisation through the professional construction of them as difficult or a nuisance, where their 'stories' were treated with intolerance and disbelief. Valerie exemplifies this unconscious way of thinking and treating black and minority ethnic women:

'I think it's their [GP's] impatience and prioritisation and how they see things – especially when they [the women] are coming back quite often for social reasons you know – presenting symptoms of headaches and pains when actually it's stress and the difficulties of life.'
(Valerie, white NHS Trust Manager, 40)

A study looking at barriers to health among minority ethnic women in the Wakefield area suggests GPs find the women difficult and demanding, with high expectations and in need of constant reassurance. They complain that the women's concept of illness is to be 'cured by a tablet' and that they seem to be looking for the 'magic pill' (Ashrafi and Brian, 1997). However, as Jan explains, the women had developed an oppositional discourse in which they knew they were being perceived as a nuisance:

'You wait so long and then they [GP's] say 'what's wrong with you' – they just give you antibiotics – they just give them to you – but I know about antibiotics – I know they are not good for you – the doctor just sees it as an easy way to get rid of you.'
(Jan, African born Goan, mother and church worker, 54, in U.K. 30 years)

It is hardly surprising that women speak of avoiding such negative interactions and attempt to seek help elsewhere. Research has shown that though ethnic minorities are at least as likely as white people to consult with their GP, they are less likely than whites to leave the surgery with a follow up appointment (Gilliam et al, 1989).

3.4.3 Diet and language

One of the manifestations of the racialisation of health is the belief that ‘other cultural practices’ are inferior to those which are practised here ‘in the West’, and thus these practices are seen as the root cause of poor health (Nazroo, 2002). This attitude is apparent in relation to diet and eating habits as Jacinta explains:

‘There is an assumption that ‘your food is inferior to ours’... we make the women conform to British foods. As a health visitor we are not told to suggest foods that the women would be familiar with. We say ‘have cereals like weetabix’... we don’t say why not use this root vegetable – which they are familiar with and which has the same health values as the processed cereals – or may have more.’
(Jacinta, African Caribbean health visitor, 42)

It is clear that food is a crucial cultural identifier among ethnic communities. ‘Ethnic’ food markets characterise inner-city areas, where the women and their families live and work. During the research, gifts of food (and clothes) were given, recipes were revealed, and meals were cooked and shared with the researcher in the homes of the women and in the community centres where they gathered. Food and female cultural identity are strongly intertwined. Hazel talks of ‘people like me ...who eat this food’, yet as a health worker both she and Jacinta are trained against the grain with an ethnocentric model of good nutritional value. As she acknowledges, this means that she misses an opportunity for engagement with the women:

‘There’s a lack of information given that is appropriate to our diet – it’s no use saying to us use low salt foods and no sugar – tell me which food that’s in that’s relevant to me... I wasn’t aware that plantain was a high carbohydrate food and in particular quite a poor type of carbohydrate – that’s important information for people like me who eat this kind of food – so it’s irrelevant showing me bog standard food and fruit – show me food that I eat and recognise.’
(Hazel, African Caribbean mid-wife and mother, 40)

Just as food is a terrain of struggle for recognition and empowerment so too is language. Issues of language and literacy frame the public health services discourse on ‘otherness’. High on the agenda for health professionals are issues of communication in terms of language information and culture when dealing with black and minority ethnic women (Ashrafi and Brian, 1997). Achieving equality for the health service was often articulated in official health service equality documentation in terms of the tangible and obvious language and communication issues, especially the need to facilitate the women’s ability to understand.

However despite the rhetoric, basic access to information and simple translations were still hard to find as Margaret explains with regard to the automated phone services used by her local hospital.

'When you make an appointment for instance you can't speak to anybody – you just have to do everything on your phone – you have to use buttons on the phone and leave your number...it would be so much easier to have someone on the phone – it's a difficult thing to do – you have to understand English to leave that message – what if you can't speak English – you haven't got a chance- not everyone is as self-sufficient as me – I can read and write – if you haven't got that then you're nothing in the system.'
(Margaret, African born in UK, mother and advocacy professional, 38)

Even though language differences and the need to access information was the dominant discourse in the health service for achieving equality, the most simple oversights remain characteristic as Jacinta and Zena explain:

'Years ago I remember sending out appointment cards for routine medical appointments when I worked as a school nurse... no one turned up... I couldn't understand why – but I found out – the parents couldn't speak or read English... this still happens – women are missing out because they don't understand the language... also on leaflets there are no directions – if you don't know the area you won't know where to go... or who to ask to get there.'
(Jacinta, African Caribbean health visitor, 42)

'There are so many leaflets – all with important information but they are never in any other languages – so how can women understand about contraception if they don't understand what they are saying.'
(Zena, Afghani mother, refugee and doctor, 34, in U.K. 5 years)

There was a huge assumption about the efficacy of literature as the main vehicle to disseminate information in the health service. In Hazel's experience, simple solutions based on 'insider' community knowledge and tapping into local entertainment and local 'ethnic media' were logical:

'We can't make the assumption that everybody can read or has the time to read... its often the last priority – reading might not be the best form of passing on information... community TV or radio – they should be tapping into these sources – it strikes me that if I want to hear any news about my community I turn on my local radio – not the mainstream one – the one appropriate to my cultural group.'
(Hazel, African Caribbean mid-wife and mother, 40)

On the surface, English language and literacy issues appear simply to be about access. However, speaking 'your' language also signifies deeper identity issues for the women in terms of being accepted for what they are, who they are, and what they have to offer.

Hazel felt that if she or her community was not ‘mirrored’ by an organisation she had difficulties in connecting with it:

‘One thing for me as a black woman – I don’t show interest in something unless it is something that mirrors myself – so even as a health professional with all my awareness if I don’t feel comfortable in an environment I won’t go – if it’s in the wrong place – the wrong side of the borough – or delivered by someone I can’t identify with, I won’t go – so we need to address this – and recognise that mirroring is a real issue.’
(Hazel, *African Caribbean mid-wife and mother*, 40)

3.5 WOMEN’S ‘OTHER WAYS OF KNOWING’

In the context of black and minority ethnic women being “marginalized from the loci of power” (Thorogood, 1989: 331), the women employed strategies to get around the health system. These were not simply ‘coping strategies’, but were grounded in self actualisation and ‘real knowledge’ derived from their lived realities of racial and gender exclusion (Mirza and Reay, 2000). As Phoenix (2001) points out, women living in a racist society develop practices which allow them to co-exist with different world-views, while keeping their alternative identity and spirituality intact.

3.5.1 Cultural strategies

The women’s narratives tell about being strong, brave, clever and dignified in the face of others’ perceptions of them as strange, stupid, manipulative or voiceless victims. In opposition to these popular constructions many women tell stories of the creative and inventive strategies they use to preserve cultural dignity. One African Caribbean woman reveals that her elderly mother, who has mobility problems after a stroke, gets up at 5.00 a.m. to clean the house very slowly if she is expecting a visit from the health visitor or social worker. Being clean and being seen to be coping is part of who she is – a proud African Caribbean elder (Patel, 1996). However as Joy (1996) shows, cultural values about greeting visitors among the disabled African Caribbean women can work against them receiving the benefits they are entitled to as their efforts were interpreted as a sign of their mobility.

In the context of limited access to rights, many women talk of cultural strategies they have evolved to ‘fight for their rights’. They construct proud and brave identities as ‘natural survivors’ and ‘challengers of injustice’. Ultimately they know this means they are seen as problematic in the ‘system’, but they have little choice as Cynthia reveals. Her son had meningitis and was hospitalised for some weeks. It took several trips to the hospital’s Accident and Emergency Department to have him diagnosed and she really had to fight to get the doctors to take his condition seriously:

'...About Dwaine and his meningitis, if I had gone on their opinions I wouldn't have a son today - I challenge things when they happen and try and get an answer ...maybe it offends people – we've had to stand up for ourselves – we've had to fight our corner – so now we just do it naturally.'

(Cynthia, African Caribbean mother and community outreach worker, 30)

Other women, those who were refugees or non-English speaking had different, less obvious strategies, but they were equally effective for their needs. Many brought friends or husbands to their hospital or doctor's appointments, not always because this was culturally desirable or due to oppressive social positioning in which men or chaperones must be present, but to help them negotiate the intolerance and dismissive doctors.

'I'm also scared to go on my own because I think the doctors are horrible...with my husband I feel more comfortable.'

(Fatma, Afghani mother and refugee, 32, in U.K. 1 year – speaking through a translator).

Many women also strategically drew on family members as 'fixers' as the main mechanism for bypassing an incomprehensible health advice system:

'I went to the Citizens Advice Bureau, but it takes a long time to help – so now I go to my nephew.'

(Mariam, Bangladeshi grandmother, 64, in U.K. 2 years – speaking through a translator)

3.5.2 Social networks, resources and support

In contrast to the black British women who have developed identities based on 'survival through challenging injustice', refugee and migrant women drew on their cultural capital to find solutions and develop unique strategies based on their transnational networks and 'survival through transcendence', as Hilda explains:

'My son... kept getting flu last year – I'd go to the doctor – he'd give antibiotics – which gave my son diarrhoea ...We went back to Poland... so we brought him to a Paediatrician – we found out that my son had a bad chest infection – bordering on pneumonia – not flu like the doctor here said – he's been fine since.'

(Hilda, Polish mother, 28, in U.K. 7 years)

Some women used their transnational networks in other ways. In response to the lack of support and help within the health service, and no means of child care to release her to re-qualify in the UK, Zena, an Afghani doctor explains how she has been active in starting up and working in an Afghani community medical centre. It is run by lecturers, doctors, and postgraduates, mostly now unemployed. She explains:

'The organisation has helped me a lot – I feel I can do something for myself – I am here 4 and a half years – at first I didn't know what to do – there was no one to show me the way – it has taken a long time to get here.'

(Zena, Afghani mother, refugee and doctor, 34, in U.K. 5 years)

Holistic and home remedies, folk knowledge and alternative health cures were other ways the women rationalised their health and well being and took control over their lives. Speaking at the older women's forum, the women felt that it was a satisfactory way around the unsatisfactory system.

'We've learnt from our mothers how to treat our colds and flu – we take ginger and cumin and whatever else we know we should – it is much better than going to the doctor.'

(Rhona, African born Goan, mother, librarian and community worker, 44, in UK 32 years)

While many of the older generation of women talked about these alternative methods to conventional medicine, they also spoke of being penalised by the health service as a result of not attending their doctor regularly. Two women said they had been taken off the doctor's register for not having attended in some time.

Most of the women interviewed in this study were involved in structured community support groups. By engaging with other women and having a space to talk, the women used these 'safe' spaces as places to develop their social capital within the system. They often used the connections they made there to enable them to find solutions to their problems such as drawing on each others skills to take blood pressure, or organise taxis to ferry them safely to community functions, or as in one case, support with diagnosing a child's rickets.

Ironically, when asked where they went to seek help in terms of equality advice and with access to the health service, none of the women consciously recognised that they were building their own bridges to equality and access. The support and information they shared was seen as 'women's business' – organic and natural. 'Seeking help' and 'getting fair and equal treatment' was explained in terms of the dominant discourse of going to a more structured organisation like the Citizens Advice Bureau (CAB). However they rarely visited these places:

'I went there once – but they were no help – so I went to another group who run a drop-in – they helped me.'

(Zara, Kosovan mother and refugee, 25, in U.K. 2 years).

3.6 INSTITUTIONAL RACISM AND STRUCTURAL INEQUALITIES

Much has been written about excluding and inequitable practices within the health service (Coker, 2001; Carter, 1999; Ahmad, 1996; Smaje, 1995) but in recent years, modernisation in the public sector has led to the conscious adoption of a discourse on equality and anti-discrimination.

3.6.1 Mapping the language of inequalities

This study included a limited investigation into the institutions that structured the women's experiences of health care. We found that when equality was raised in the health service it was clearly centred on the notion of social inclusion through 'meeting needs and facilitating access'. Health care organisations employed 'the language of inclusion' which as Valerie demonstrates, is characterised by being flexible, embracing difference, and working in partnership. Such a progressive institutional identity, which embodies 'all the right things' is however at odds with the language of 'objectives and targets' which is used to drive the agenda forward as Valerie explained:

'The whole health service is very target led and when you have targets it can actually reduce your capacity to meet diversity because you have to put a lot of effort into one specific area – and there are bad ways of doing that where a waiting time for one service can be reduced by increasing it in another service – but the other service isn't being monitored so you know you look like you're doing well.'
(Valerie, white NHS Trust Manager, 40)

This emphasis on targeting and auditing highlights the contradictions of delivering equalities in a climate of profit and business within an increasingly privatised health service. Under these conditions black and minority ethnic women slip through the cracks of a crude equalities accounting system which fails to recognise the complexities of implementing gender blind 'race' targeting on one hand and colour blind gender targeting on the other. Black and minority ethnic women become invisible in an equalities agenda that focuses on either ethnic minorities or women at any one time, but rarely both at the same time (UN, 2000; Mirza, 2003).

'Generally there is a greater awareness [of black and minority ethnic women] but how high up the priority list it is, is questionable.'
(Valerie, white NHS Trust Manager, 40)

Hazel commented that though there was now a greater awareness of the issues surrounding black and minority ethnic women, a lot more work needed to be done:

'In my experience as a midwife things like specific medical problems related to ethnic groups like sickle cell or thelassaemia... there is a lot more awareness... but in practice... well it's not put into practice... there's a lot of information and training and whatever but when it gets down to the nitty gritty of providing there is a way to go... the translation of information has to be developed.'

(Hazel, African Caribbean mid-wife and mother, 40)

3.6.2 Tracking equal opportunities

The daily experiences of black and minority ethnic women health care workers highlighted the persistent inequalities they faced at work, despite the rhetoric of equal opportunities:

'They have an equal opps. policy – or at least they say they have... but opportunities are not equal here for workers or service users...promotion is never fair in terms of black women... black women don't seem to get beyond a certain level... there is a token gesture but they don't go beyond that.'

(Jacinta, African Caribbean health visitor, 42)

While the introduction of equal opportunity policies in the health service has been significant at a symbolic level (Johnson 1996), there is little evidence to suggest that the policies have had a marked impact on breaking the cycle of discrimination and disadvantage experienced by non-white workers in the health service. As Carter explains, minority ethnic nurses “are located in the least desirable types of nursing and on the least desirable shifts...and few reach management positions” (1999: 58). Valerie gives us a clue as to why. She explains:

'It [the equal opportunity policy] is as effective as the manager makes it – there's no pressure from above about equality targets – not about equality.'

(Valerie, white NHS Trust Manager, 40)

The reality of low status work among black and minority ethnic nurses hits home when Hazel tells a story of mistaken identity:

'There is an automatic assumption that when we walk into a room the black person is more than likely the lower grade... It's happened to me ... when I was a staff nurse way back when a doctor came in the ward... I had the white staff nurse dress on and a student nurse had the blue student dress on – but the doctor went straight to the student nurse... and you could only assume this was because she was white.'

(Hazel, African Caribbean mid-wife and mother, 40)

3.7 UNPACKING INSTITUTIONAL RACISM

In the study, the black women working within the health service were being subjected to institutional constraints that they experienced at personal level. Jacinta experienced a form of 'cultural containment' (Hill Collins, 1998) when she applied for study leave. The official criteria of 'no precedent, no special treatment' failed to acknowledge her identity and duties as a breadwinner and mother:

'They [the employers] give options of unpaid leave – but how can I study without a salary – and run my family home with no money... we don't get rewarded for our desire to improve ourselves – I wanted to do a course that would really help my work – but I wasn't allowed – I was told it would set up a precedent – and that was the end of that.'
(Jacinta, African Caribbean health visitor, 42)

Hazel, a midwife for 20 years, explains that this process of needing more grades and qualifications has cemented the process of racial exclusion for black nurses in the last 10 years. Whereas there were more black nurses in senior positions as sisters when she first worked in the NHS, she argues that this process is now reversed with black health workers becoming increasingly invisible in management positions.

The combination of official obstacles, hoops and 'insider knowledge and networks' on one hand and cultural and gendered insensitivity on the other, amounts to what the Macpherson report describes as 'Institutional Racism'. In this process a person is denied their right to equal opportunity because of their 'race' or ethnicity. Unwitting processes, attitudes and behaviours underpin discrimination and prejudice within an organisation (Macpherson, 1999: 28).

Jacinta was clearly caught in an institutionally racist 'trap'. Her cultural commitment to her family as an African Caribbean woman was at odds with the individualism of achievement and success which defined the masculine career structure of the organisation for which she worked. Rather than the organisation taking responsibility for this structural lacking, she is pathologised as unambitious:

'We don't have extended families – so if there is a sick child we have to stay at home to look after them – we are penalised for staying with our families. We are not seen as power hungry – but that's because we have so many other commitments – it doesn't mean we don't want to succeed. We don't have the time to network or get inside information ...so how can we move up if we're not in the right environment... it's a catch 22 situation.'
(Jacinta, African Caribbean health visitor, 42)

3.7.1 Understanding 'equality' versus 'difference'

As Jacinta pointed out, dealing with difference is a catch 22 situation within the health system. Are people treated equally by treating them all the same, or by recognising their difference? Cynthia highlights this conundrum when she expresses the dual need for belonging and recognition:

'We [African Caribbean black women] don't feel we're different to anyone else and so we should be treated the same...'

But on the other hand she says:

'If you've got someone coming from a troubled country or a third world country they will have special needs – and it's important not to lump all those together ... like some women might find it difficult to be examined by a doctor – some women might not be comfortable with that – every client has needs really – and you just can't make generalisations – you need to take each client on their merits – not as a whole population.'

(Cynthia, African Caribbean mother and community outreach worker, 30)

As the Commission on the Future of Multi-Ethnic Britain conclude in their report (Runnymede, 2000), getting the balance right between 'equality' and 'difference' is the equality challenge for the health service in the 21st century.

3.8 CONCLUSIONS

This study has focused on black and minority ethnic women's multiple identities in the context of their strategies to maintain health and well being as users and employees of the health service in Britain. It explored the ways in which the specific situations and lived realities of the women's lives impinged on their right to appropriate care and equal treatment in the health service.

3.8.1 Multiple identity and the 'equality agenda'

To explore multiple identity as a means of understanding the process of social exclusion and inequality was revealing. The ways in which the women expressed their experiences of poverty, neglect, marginalisation and discrimination were not through an overt equalities discourse where identity was expressed in terms of being women, or black, or a refugee, or young, or old, or disabled, or gay. Such 'intersectionality' (Crenshaw, 1993; UN, 2000) which characterises the official equalities debate artificially separates out our combined racial, gendered and other identities, cutting across our natural multiple identities as experienced in daily life (Maynard, 1994).

In the women's daily, lived experiences they expressed their identities in the collective gendered terms of familial roles and responsibilities as mothers, workers, and wives.

They talked about duty to the family, protecting their children, and surviving poor conditions, caring for others and organising for change. They expressed themselves as 'holistic feminised beings' who were active and self motivated, but also spoke of their frustration at the services and treatment they received.

Despite progressive equality legislation, it has been demonstrated that black and minority ethnic women are still categorised in ways which do not relate directly to the application of the equality legislation. As a consequence they have been found to suffer cumulative multiple discrimination (Fredman, 2002; UN, 2000), double or triple jeopardy (Bradley, 2001; Gregory, 2002). This means they often fall between the scope of the separate legislative provision for race, sex and disability.

In the study we found that cultural assumptions and preconceived attitudes about the women obscured their right to be seen as individuals. In the doctor's surgery they were defined through childcare or inability to speak English – thus they were seen as 'black single mothers' or 'demanding Asian women' before they were seen as a person. Understanding the way in which this particular social construction of 'difference' manifested itself in the women's lives is the key to understanding the process of exclusion in the health service. The women's 'difference' in terms of language, diet, and ways of childcare framed how they were perceived in the health care system – this study found that they were universally seen as a 'problem'. There was a crude cultural reductionism that underpinned this way of thinking and ironically, the cultural problem was also seen as the solution – access to language and changing the women's diets were the focus of 'good practice'.

3.8.2 Health inequality and (un)equal access

The health service has adopted the language of equalities through their strategy of 'respecting diversity and recognising difference'. However, although they had instituted some mechanisms for ethnic monitoring, community partnership and access to information through targeting and enforcement, they did not appear to have the practices in place for achieving real equality of treatment. Black and minority ethnic women were marginalized as patients through the embedded institutional processes inherent in the 'racialisation of health'. This included professional prejudice and medical, cultural and social presumptions which marginalized the women's health issues and inhibited their access. As staff, the black women felt that they rarely enjoyed equal opportunities, which they experienced as rhetoric not practice. Direct and indirect institutional practices ensured they had little access to routes to promotion and professional development.

The state provision of equality services, such as local advice centres, were not considered by the women as having any bearing on their lives. Seeking an individual legislative remedy or lodging official complaints about their daily experience of marginalisation was not high on their agenda. The women had adopted other ways around the system. They challenged negative cultural assumptions of their passivity and

'disengagement' by developing amazing strategies of self help, personal motivation and networking. Their strategies, which embodied a sense of dignity, served to mirror that which was lacking in the services. Such creativity and self-help was however not valued or developed in the health service, which operates a top down approach to equalities.

3.8.3 A multiple identity approach

This study illuminates the value of a multiple identity approach in the context of a new, far reaching and expanding equalities agenda. Recently the Race Relations Amendment Act (2000), the 1998 Human Rights Act, and the EU Race and Employment Directives (2000) have widened anti-discrimination, equal treatment and positive provision (Hepple, 2000; DTI, 2002; Fredman, 2002). Protection now can cover direct and indirect discrimination based on sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth, racial or ethnic origin, religion or belief, disability, age and sexual orientation.

Such extensive protection needs to be accessible to the most marginal and excluded if it is to be credible. The findings of this study indicate that a gap remains between policy and legislation on one hand and practice and delivery on the other. At the heart of this gap is the lived experience of black and minority ethnic women. It is their stories that light the way through the maze of what has become the 'equalities agenda'.

NOTES

- 1 In this study we use the popular and 'official' term 'Black' and minority ethnic women. This is not a term women tend to use themselves, and there is much controversy about what it really signifies and to whom (Modood et al, 2002). It has evolved due the complex and political nature of racial definitions. In the social construction of identity it is argued that there is no scientific or biological foundation for racial difference. Thus 'Black' is not a 'race'/racial category, but a politically contested homogeneous term which has come to mean those who are visibly and politically racialised as 'other'. It has been appropriated positively by some groups, such as 'black' African Caribbean women and politicised British non-white women to identify themselves (Brah, 1996; Mirza, 1997). Ethnicity on the other hand, includes self-defining religious and cultural groups, who can be similarly racialised as culturally defined groups. Because of differential power among and between ethnic groups, inherent differences in worth may not necessarily apply in the same way as with 'Black' groups (Cornell and Hartmann, 1998; Runnymede, 2000). However, while those defined as 'ethnic' make up majority populations globally, they find themselves defined as small 'minority' migrant communities in the UK, hence the term 'minority ethnic'.
- 2 The women draw on 'social capital' (networks) and cultural capital (education) both of which are socially and economically determined. The material and

- symbolic significance of different types of social, cultural, physical and economic capital explain the production and reproduction of social class (Bourdieu, 1986). Access to different forms of capital is determined by the women's social location. The women develop social capital such as friendships, community contacts, family and neighbours which provide access to valuable resources which help compensate for lack of state provision in terms of their access to cultural capital (i.e. education and wealth). They work to create affective ties to help enhance their communities' stock of social and cultural capital (Mirza and Reay, 2000).
- 3 Each interview took about 1 hour and the discussions were taped. Gaining access, building trust and overcoming language difficulties are all research issues we have encountered in the process. Anonymity and confidentiality have been maintained throughout the research – all names, including the places, have been changed.
 - 4 However, the statistical categories do not necessarily give us a clear picture of women in Multiethnic Britain. 'White' ethnic groups such as Irish, Southern and Eastern European are often subsumed under 'White'. Turkish and Middle Eastern communities are classified as 'Asian Other', while significant new migrant and refugee communities, such as Somali are categorised under 'Black Other'. Similarly new and growing identities that reflect social change and complex multiplicity among minorities in the UK are defined simply as 'Mixed Race' in the 2001 Census. This analysis is from the Labour Force Survey Spring 2002, Office for National Statistics, as 2001 Census data disaggregated by sex and ethnicity were not available at the time of writing (March 2003).
 - 5 There are 'ideologies of femininity' which circulate in art, media, schools, law, science and medicine and popular culture which permeate our common-sense everyday thinking about what a woman should be (Woodward, 1997). However, there are different ideological constructions of black and white femininity (Mirza, 1997; Alexandra and Mohanty, 1997). The ideological regulation of third world women who do not fulfil the expectation of an idealised Western model of femininity is just one way in which Black and minority ethnic women have been constructed. As Alexandra and Mohanty argue, third world women's bodies are 'disciplined', that is brought in line with gendered ideology, in many different ways. In nationalist representations women are expected to be 'guardians of culture' and idealised as 'bearers of races'. In state constructions of the nuclear family they are represented as compliant 'wives and mothers'. In contrast to the Western image of the 'bad working mother', armies of third world mothers are deemed 'good workers' when their legendary 'docility' maximises globalised capital investment and profit.

REFERENCES

- Acheson, D. (1998) *Independent Inquiry into Inequalities in Health Report*. London: The Stationary Office
- Ahmad, W. I. U. (1996) 'Making Black People Sick: 'Race', Ideology and Health Research', in W. Ahmed (ed.) *'Race' and Health in Contemporary Britain*. Buckingham: Open University Press.
- Alexander, J. and Mohanty C. T. (eds.) (1997) *Feminist Genealogies, Colonial Legacies, Democratic Futures*. London: Routledge.
- Ashrafi, K. H. and Brian, A. (1997) *Report of Ethnic Minority Women's Health Project to Identify the Barriers Experienced by Ethnic Minority Women in Accessing Primary and Secondary Health Care Services in the Wakefield Area*. Wakefield: Wakefield HA.
- Berthoud, R. (2001) 'Teenage births to Ethnic Minority Women' in *Population Trends* 104 (Summer): 12–17.
- Bhavnani, R. (1994) *Black Women in the Labour Market: A research review*. Manchester: Equal Opportunities Commission.
- Bourdieu, P. (1986) 'Forms of Capital' in J. Richardson (ed.) *Handbook of Theory and Research for the Sociology of Education*, New York, Greenwood Press.
- Bradley, H. (2001) 'Handling Double Disadvantage: Minority Ethnic Women and Trade Unions', ESRC www.regard.ac.uk
- Brah, A. (1996) *Cartographies of Diaspora: Contesting Identities*. London: Routledge.
- Bryan, B., Dadzie, S., and Scafe, S. (1985) *Heart of the Race: Black Women's Lives in Britain*. London: Virago.
- Carter, J. (1999) 'Ethnicity, Gender and Equality' in R. Barot, H. Bradley and S. Fenton (eds.) *Ethnicity, Gender and Social Change*. London: Macmillan Press.
- CCCS (1982) *The Empire Strikes Back; Race and Racism in 70's Britain*. Centre for Contemporary Cultural Studies. London: Hutchinson Press.
- Chahal, K. and Julienne, L. (1999) *"We can't all be white!" Racist Victimisation in the UK*. Joseph Rowntree. London: Routledge.
- Coker, N. (2001) (ed.) *Racism in Medicine – An Agenda for Change*. London: Kings Fund.
- Cornell, S. and Hartmann, D. (1998) *Ethnicity and Race: Making Identities in a Changing World*. London: Sage.

Crawley, H. (2001) *Refugees and Gender: Law and Process*. Bristol: Jordon Publishing.

CRE (2002) *Ethnic Minority Women: Fact Sheet -1997*, Commission for Racial Equality, available at <http://www.cre.gov.uk/facts> (accessed 20 June 2002).

Crenshaw, K. (1993) 'Whose Story is it Anyway? Feminist and anti-racist Appropriations of Anita Hill' in T. Morrison (ed.) *Race-ing, Justice En-gendering Power*. London: Chatto and Windus.

Dale, A., Fieldhouse, F., Shaheen, N. and Kalra, V. (2002) 'Routes into Education and Employment for Young Pakistani and Bangladeshi women in the UK', in *Work, Employment and Society*, 16(1): 5-27.

DTI (2002) *Equality and Diversity: The Way Ahead*. HMSO: London. Available from: <http://www.dti.gov.uk/DTI/Pub6351/30k/10/02/NP>

Fredman, S. (2002) *The Future of Equality in Britain*. Manchester: Equal Opportunities Commission (GB).

Gregory, J. (2002) 'Discrimination, Equality and Human Rights: Dilemmas and Contradictions'. Middlesex Research Seminar, May, Middlesex University.

Gilliam, S., Jarman, B., White, P. and Law, R. (1989) 'Ethnic Differences in Consultation rates in urban general practice', in *British Medical Journal* 299: 953-957.

Hepple, B., Cousse, M. and Choudhury, T. (2000) *Equality a new framework: Report of the Independent Review of the Enforcement of U.K. Anti-Discrimination Legislation*. Oxford: Hart Publishing.

Hill Collins, P. (1998) *Fighting Words: Black Women and the Search for Justice*. Minneapolis: University of Minnesota Press.

Johnson, M. (1996) 'Equal Opportunities in Service delivery: Responses to a changing Population?' in W. Ahmad (ed.) *'Race' and Health in Contemporary Britain*. Buckingham: Open University Press.

Joy, F. (1996) "Fight on all sides: Black Disabled women", in *Community Care*, 1135 (29th August): 12-13.

Law, I. (2002) *Race in the News*. Basingstoke: Palgrave Press.

Macpherson, W. et al. (1999) *The Stephen Lawrence Inquiry: Report of an Inquiry by Sir William Macpherson of Cluny*. London: Stationary Office.

Mason, D. (2000) *Race and Ethnicity in Modern Britain*. Oxford: Oxford University Press.

Maynard, M. (1994) 'Race', Gender and the concept of difference' in H. Afshar and M. Maynard (eds.) *The Dynamics of Race and Gender: some feminist interventions*. London: Taylor and Francis Ltd.

Meadows, L., Thurston, W. and Melton, C. (2001) 'Immigrant Women's Health', in *Social Science and Medicine* 52: 1451-1458.

Mirza, H. (1997) 'Mapping a Genealogy of Black British Feminism' in H. Mirza (ed.) *Black British Feminism*. London: Routledge.

Mirza, H. (2003) "All the women are white, all the blacks are men: but some of us are brave" – Mapping the consequences of invisibility for black and minority ethnic women' in D. Mason (ed.) *Explaining Ethnic Inequalities*. Bristol: Policy Press.

Mirza, H. and Reay, D. (2000) 'Redefining Citizenship: Black Women Educators and the Third Space' in M. Arnot and J. Dillabough (eds.) *Challenging Democracy: International Perspectives on Gender, Education and Citizenship*. London: Routledge Falmer.

Modood, T., Berthoud, R. and Nazroo, J. (2002) 'Race', Racism and Ethnicity: A Response to Ken Smith' in *Sociology* 36 (2) May.

Mohanty, C. T. (1997) 'Women Workers and Capitalist Scripts; Ideologies of Domination, Common Interests, and the Politics of Solidarity' in M. J. Alexander and C. T. Mohanty (eds.) *Feminist Genealogies, Colonial Legacies, Democratic Features*. London: Routledge.

Nazroo, J. (1998) 'Genetic, Cultural or Socio-Economic Vulnerability? Explaining ethnic inequalities in health' in M. Bartley, D. Blane and G. D. Smith (eds.) *The Sociology of Health Inequalities*. Oxford: Blackwell.

Nazroo, J. (2002) 'The racialisation of ethnic inequalities in health', in D. Dorling and L. Simpson (eds.) *Statistics in Society*. London: Arnold.

Nettleton, S. and Burrows, R. (1998) 'Mortgage Debt, Insecure Home Ownership and Health: An Exploratory Analysis', in M. Bartley, D. Blane and G. D. Smith (eds.) *The Sociology of Health Inequalities*. Oxford: Blackwell Publishers.

Owen, D. (1994) *Ethnic Minority Women and the Labour Market: Analysis of the 1991 Census*. Manchester: Equal Opportunities Commission.

Patel, N. (1996) 'Healthy Margins: Black Elders' Care: Model, Policies and Prospects', in W. Ahmad (ed.) *'Race' and Health in Contemporary Britain*. Buckingham: Open University Press.

Phoenix, A. (2001) 'Research Review: Children, Families and Young People'. *Rowntree Research Seminar, Reviewing Research on Black and Minority Ethnic Communities*. July 2001, York.

Rassool, N. (1997) 'Fractured or Flexible Identities? Life histories of 'Black' diasporic women in Britain', in H. Mirza (ed.) *Black British Feminism*. London: Routledge.

Reay, D. (1998) *Class Work: Mother's involvement in their children's primary schooling*. London: University College Press.

Reynolds, T. (1997) '(Mis)representing the black (super)woman', in H. Mirza (ed.) *Black British Feminism*. London: Routledge.

Runnymede Trust (2000) *The Parekh Report: Commission on the Future of Multi-Ethnic Britain*. London: Profile Books.

Simmonds, F. (1997) 'My Body Myself: How does a Black Woman do Sociology', in H. Mirza (ed.) *Black British Feminism*. London: Routledge.

Smaje, C. (1995) *Health Race and Ethnicity: making sense of the evidence*. London: King's Fund.

Thorogood, N. (1989) 'Afro-Caribbean Women's Experience of the Health Service', in *New Community* 15 (3): 319-34.

UN (2000) 'Gender and Racial Discrimination'. Report of the Expert Group Meeting, *UN Division for the Advancement of Women*, 21-24 November 2000 Zagreb Croatia (Submission by K. Crenshaw).

Vaz, K. (1997) *Oral Narrative Research with Black Women*. London: Sage.

Westwood, S. and Bhachu, P. (eds.) (1988) *Enterprising Women: ethnicity, economy and gender relations*. London: Routledge.

WEU (2002) *Key Facts: Ethnic Minority Women in the UK*. London: Women and Equality Unit available at:
http://www.womenandequalityunit.gov.uk/research/index.htm#min_eth_briefing

Woodward, K. (1997) (ed.) *Identity and Difference*, London: Sage and OUP.

4 IT'S NOT JUST ABOUT RAMPS AND BRAILLE: DISABILITY AND SEXUAL ORIENTATION

Michael Brothers

4.1 INTRODUCTION

4.1.1 Scope

The intention of this qualitative research was: to explore the social profile of the situation and identity of disabled people who have a sexual orientation that is lesbian, gay or bisexual (LGB). It focuses on how this grouping understands who they are, and the issues that are of concern to them as LGB disabled people. It also draws on the views of experts who represent the interests of both LGB and disabled people, whilst also drawing on the views of National Health Service (NHS) staff with regard to their perception of those who hold this particular multiple identity.

This study was conducted by the Disability Rights Commission (DRC) in association with Stonewall (which supports and represents the interests of LGB people) and Opinion Leader Research, utilising a methodology of focus groups and telephone interviews – comprising of 10 LGB disabled people, 5 health professionals and 3 experts.

4.1.2 Findings

This research found that people construct self identity by making choices of personal self determination and by their experiences of exclusion. Findings derived from the views of health professionals emphasise the reality of prejudice in the NHS and how this is manifested. Finally, the report concludes by noting the extensive discrimination faced by this social group and makes recommendations.

This study demonstrates the complexity of self identity – not in a static way, but as a shifting and changing sense of belonging. Different aspects of one’s identity may be relevant or passive, depending on the circumstances at the time. This creates a notion of unravelling and interwoven strands, coupled with a sense of fluidity, interaction and multiplicity, ultimately shaping people’s identity:

“Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race ... everything finally piling into a single human body.” (Clare, 1999)

4.2 THE INTERSECTION OF DISABILITY AND SEXUAL ORIENTATION

4.2.1 Context

The social model of disability, developed by the Union of Physically Impaired Against Segregation (UPIAS) some 30 years ago, articulates that policies, procedures and practices are the “problem”, rather than individual impairments of function (Shakespeare et al, 1996). Disabled people are excluded from society by widespread discriminating policy and practice – for example, inaccessible transport and low employment opportunities (Barnes, 1991). However, disadvantage is not caused by structural barriers alone, but also by the implications of varying impairments when

interacting with others. How society responds to this combination (both difference and barriers) determines isolation or inclusion (Shakespeare et al, 1996). A participant in our study said:

'I've actually been turned down at the doctors, because I was a lesbian. They said they were full up but my friend went the day after, because we both moved into the same place and she's actually a lesbian but she looks very, very, straight and they signed her up straightaway. I just didn't have the energy [to complain] because, I mean, you get to a point where you just think, well what's the point, because you know nothing's going to change.'

LGB people are stigmatised, not just by moralising about what they might do, but by fear and myth of what it means to be gay or lesbian (Harley et al, 2000). Breaking free of the closet is difficult for anybody, but the sense of isolation and pressure of authority makes “coming out” even harder for disabled people (O'Toole, 1996). However, concealment is not simply about shame, but can also be a sanctuary of pleasure. Whilst recognising the positive experience of liberation from the closet, Stonewall culture developed over the last 30 years should not alienate or victimise people hiding their identity.¹ It may be a political act to “come out”, but one's self identity remains whether concealed or declared (Seidman, 1998).

4.2.2 Identity: who am I?

Sexuality and Disability

There are 8.5 million disabled people in Britain (Grundy et al, 1999). There are no reliable statistics about the numbers of gay or lesbian people in Great Britain or Ireland (due to fear of coming out). However, using a very conservative assumption that 3% of the population are homosexual, there are an estimated 1.8 Million LGB people (Stonewall and Mori, 2002 – unpublished). Making a very crude calculation on these figures, suggests that there are about 255,000 LGB disabled people in Britain.

Regardless of sexuality, disabled people continually come up against negative messages that they are not suitable romantic partners. Segregated education, for example, limits interaction with non-disabled children and reinforces negative stereotypes about disabled people being asexual (Finger, 1992; Shakespeare et al, 1996; Thompson et al, 2001).

Opportunities to interact socially with others, let alone chances to be sexually intimate, are only too scarce for many disabled people. It is challenging enough for society to accept that disabled people have sex, but quite mystifying for it to contemplate that they might engage in same-sex relationships (Porter, 1987; Tilley, 1996).

People can also experience emotional turmoil because they are trying to deal with the consequences of a progressive impairment, whilst in a dilemma about whether to “come

out” sexually. This is likely to have considerable implications in terms of conflict – for example, reactions from family or friends and what all this might mean for managing their religious convictions. Furthermore, special education and other segregated systems create informal networks, often having values which are hard to break away from or do not accommodate difference (Harley et al, 2000). One interviewee in our research suggested:

‘The biggest issue with the disabled community is religion. It’s like you were bad in your previous life and that’s why you’re disabled. It’s particularly bad if you were brought up in religious schools or homes. Also all this stuff about Lourdes curing us – it doesn’t help.’

Instead of facing these hard questions, many people fabricate a heterosexual identity (counterfeiting) or reveal nothing about their personal relationship preferences (avoiding or passing). These tactics cannot be applied to disability, especially for someone with a visible impairment. Passing a hidden impairment is quite common though; whilst it seems straightforward for disabled people to avoid identifying as gay or lesbian, because society largely perceives them as being asexual, child-like and innocent (Harley et al, 2000). Another participant in our research told us:

‘I think that it depends on the nature of the disability, for example, some people have a very visible impairment and can’t escape the reactions of others whereas obviously lesbian and gay people can choose to be hidden about their sexuality so that’s one important difference.’

Gender and Sexual Oppression

Clearly, disabled women experience greater social oppression than do men (Morris, 1989). This is due to perceptions of femininity and disability both being “passive” (Oliver, 1990; Tilley, 1998). Meanwhile, the implied strength of masculinity conflicts with the vulnerability associated with disability (Morris, 1991). Disabled men often have close relationships with non-disabled women, because they are seen as asexual and safe. Moreover, feminist thinking takes inadequate account of disability, although there are closer bonds and common issues between disabled and non-disabled lesbians – for example, maintaining the role of mother (Morris, 1991; Tilley, 1998). Consequently, it is important to understand gender identity in the context of disabled people’s experience; not least in the ways this may influence sexuality and self-image (Shakespeare et al, 1996).

The Protection Problem

Parents, carers and professionals seek to protect disabled people, to the extent of suspending them in childhood. Ignoring the “problem” of developing sexual relations often leads to vulnerability, especially for people with learning disabilities who may hide their sense of guilt because they think sex is “naughty” and they would face punishment as a consequence. The evidence not only refutes, but also in fact undermines, the

popular myth that ignorance is the best form of protection. Instead, people are more susceptible to abuse (Cooper and Guillebaud, 1999).

People with learning disabilities are particularly vulnerable to the influence of others, whether it be nurturing or rejecting their sexuality (Hutchinson and Tennyson, 1986 and Corbett and Barton, 1992). The result is often diminished self-esteem, especially when confronted with negative stereotypes when “coming out” (Cambridge and McCarthy, 1997; Hodges and Hutter, 1974). One of our focus group participants explained:

‘A lot of the issues [with healthcare provision] are linked to information. The GP just wouldn’t ask about your sexuality because [the GP thinks] disabled people don’t have sex. If you were to announce ‘I’m gay’ they would probably just think that you were having an identity crisis, you were schizophrenic or seeking attention! And it would definitely be marked on your notes as that. I always tell people not to come out to their GP. They can then use it against you. It can affect housing benefit and incapacity benefit.’

This is often compounded by inadequate guidance, as support systems fail to encourage safe sex – for example, dealing with the undoubted hazards of “cottaging”. Parents, carers and professionals supporting people with learning disabilities are mistaken to victimise or alienate them, but should instead provide balanced guidance about safe sex and induction into the gay community or sexual sub-cultures (McCarthy and Thompson, 1994).

Restricting opportunities for fulfilling and consensual intimacy rarely works. Disabled people face the greatest levels of oppression when living in residential care. Foremost amongst concern is the lack of privacy. Moreover, control is managed through mandatory room sharing and policies forbidding sex between residents (Cook, 2000).

Experiences of Discrimination – Employment

The experience of employment is dependent on both the nature of people’s impairment and whether they are out in the workplace. Some participants are working either full or part time. An interviewee told us:

‘I suppose in some senses lesbians and gays can normally pass so they don’t have to reveal their sexuality so they’re not necessarily so cut out from employment and possibly other areas of life. Whereas a disability is not always, but often is, quite physical so people can’t and don’t wish to disguise it and I think that sort of locks a lot of people out of employment. So I would say that, if you looked at employment you would find there’s more lesbians and gays employed probably in better jobs as a whole than people with disabilities although that may often be at the price of keeping quiet about their sexuality.’

Experiences of Discrimination – Access to Services

The main barrier to accessing services for many LGB disabled people is primarily physical access and the perceived assumptions that medical professionals make about disability. Because many choose not to disclose their sexual orientation they feel it is hard to judge whether it affects access to services in the same way. However there is a strong sense that disclosing their sexual orientation would lead to being excluded from services or being treated in a negative way. Confidentiality is a key issue, both on a personal level but also because of the knock-on effects on things like financial services. A couple of disabled gay men told us:

‘So lots of people are not out to their doctors and lots of doctors still think being gay is a pathological condition.’

‘For gay men generally if you’re open to your doctor about your sexuality then there are all sorts of issues for confidentiality when you apply for various financial services and if your doctor knows you’re gay then you’re going to have to pay extra premiums and so on.’

There are numerous examples of people’s impairments or sexual orientation leading to perceived differential NHS treatment (illustrated below by several contributions to our study). In many cases the issue of “coming out” to GPs is central.

Physical access

‘My GP’s surgery has just been rebuilt and they put in those really high reception desks so I have to wave over the top of it.’

Recognition of partner and chosen family rights

‘Family only visiting hours in hospital can be a problem if the biological family don’t recognise the chosen family.’

Noting of sexual orientation in medical records

‘I’ve had two occasions where, the fact that I was a lesbian has been written on my notes and written in letters between GPs and mental health services when I felt like it wasn’t relevant.’

Homophobia

‘I was trying to tell my GP [about being gay] who I had had for a year as he kept trying to flog me birth control. I tried to hint by saying that I did counselling for [a gay and lesbian group] and he said “Yes I imagine those sorts of people would need a lot of counselling”. I could hardly tell him after that.’

Sexual health advice not given on account of an impairment

'At the ordinary [women's reproductive health] clinics they assume that I don't have sex. I don't tell them otherwise because they are known to be homophobic.'

Sexual health – being unable to talk about the implications of certain sexual practices openly

'If you're worried about something like thrush, you couldn't talk openly to your GP about the sexual practices that might cause it whereas you could with a lesbian doctor. I imagine it's the same for gay men.'

Information

'There is a lack of sexual health information, even general health information aimed at disabled women and disabled lesbians. What is produced in Braille and tapes seems to go like hotcakes.'

Being unable to see a female health professional

'They're dismissive. What they don't seem to recognise is that, you know, we have a culture. If you're a black person, or from an ethnic minority, as a woman you might want to see a woman doctor, for example, and that's OK and it's accepted these days but if you're a lesbian, they just don't, they can't see the significance.'

4.2.3 Belonging: who is my community?*The Disability Movement*

Even if disabled people hadn't been denied the basics of sex education, it would still prove difficult to find someone with whom to do it. Most people meet their partners at college, work or social events. Low participation levels of disabled people in further and higher education or employment reduces disabled people's chances to interact and meet potential partners. High levels of poverty amongst disabled people also constrain their ability to participate in social events, coupled with inaccessible premises and information (Shakespeare, 2000).

The social model has emerged against this background, helping to fuel campaigns to combat discrimination. The quest for emancipation has been a collective response to systemic oppression faced by both disabled men and women. As a result, the personal dimension of disabled people's lives (inclusive of sexuality) have been largely ignored.

Having tapped into the consciousness of labour and trade unionism, activists have been rather macho in their approach – manifested by adopting confrontational positions and tactics. It is also due to rational priorities set by the disability movement, in an effort to eradicate rampant discrimination (Morris, 1991; Shakespeare, 2000).

Despite progressive approaches to disability rights, LGB disabled people report widespread homophobia and prejudice in the disability movement. Organisations, such as Regard, have played an invaluable role in seeking to combat negative attitudes amongst heterosexual disabled people. In essence, the disability movement mirrors the attitudes of mainstream society, having the same prejudices about sexual orientation and gender roles (Morris, 1991; Vernon, 1999). As one of our research participants put it:

'There are a lot of people I know in the disability movement who daren't come out in their organisation.'

The LGB Community

The gay and lesbian press (Pink, Diva and Gay Times) and other media sources promote images of beauty and sophistication. Many disabled people find it difficult to identify with such portrayal. Many face the dichotomy of reaching high standards of grooming and social etiquette, only to feel rejected by the LGB community (Davidson-Paine and Corbett, 1995; Thompson et al, 2001). Body fascism is now being experienced by disabled lesbians, as the value of image is not so exclusive to gay men (Shakespeare et al, 1996). A focus group participant said:

'I don't want to sit here and slate the gay scene but it is body based. Just look at the covers of any of the magazines for a start. It makes me cautious about being on the gay scene. I don't go clubbing any more.'

In response, disabled people need to consider how they wish to be perceived. Developing positive – sexy, life affirming and passionate – images can be an effective tool for self-empowerment (Davies, 2000). Instead of fitting into a stereotypical image of beauty, it is for disabled people to be more confident and happy, feeling sexy as a result (Shakespeare et al, 1996).

Nonetheless, gaining self-confidence for LGB disabled people is not sufficient. Prejudice towards disability is still quite evident on the gay scene. Discriminatory practices and policies apply here, just as much as in wider society. Physical access to gay clubs is often difficult and safety policies prevent their participation in a range of cultural events. This was a common experience amongst our research participants, a few of them telling us:

'If you can't get into a building at all, if you can't get into a bar or into a place of work because of your impairment, or rather because the place is inaccessible to people with your impairment, then you can't express anything. So in a sense it may be that the disability is the first barrier so therefore it's more important, you know, people don't have the luxury of being able to express their sexuality because they don't have the basic right of access to the same places as other people.'

'When [my partner] had a guide dog we were refused entry from places, sometimes I couldn't tell whether or not it was homophobia that inspired that, or whether or not if we'd been Mr and Mrs Nice with a guide dog, we would have been allowed in.'

Self help groups have significant challenges here, to secure greater participation of disabled people in the LGB community (Shakespeare et al, 1996). One of our research participants told us about the experience of a disabled lesbian:

'A friend of mine rang up a lesbian social group and went along to a meeting. She gets there and it's on the top floor of the restaurant. She has cerebral palsy but could just about make it up the stairs. But she didn't feel she could ask them for help carrying a drink. You always have to put yourself on the line at those sorts of groups. You know you'll get blank looks and people think "oh I can't be bothered with her".'

Movement or community?

Finding an identity and a community can be particularly difficult for people who are both disabled and also lesbian or gay. The LGB scene does provide a lifestyle and sense of community to people, although participation is hugely difficult for disabled people. The disability scene is more of a movement for campaigning than a community to support a sense of social identity. An exception to this is the deaf community, which is a vibrant social network of people with a strong sense of self identity (O'Toole, 1996).

Whilst most people contributing to this study identified with the 'labels' of disabled person and lesbian, gay or bisexual some stressed the importance of these not being the primary facets of how they are seen. One suggestion was that these labels only become important when either of those identities are under threat. A contributor to our research said:

'I'm a bit reluctant for those things to be the first things they know about me. I also happen to like reading. If I hang on the labels too much they can damage me.'

Many LGB disabled people do not feel comfortable in either the disability movement or lesbian and gay community. They feel most secure amongst other LGB disabled people, with whom they could share experiences and not be judged, drawing on these respective political and social dimensions. Nonetheless, people with varied impairments will not necessarily understand the needs and experiences of other disabled people, who might encounter different forms of prejudice and barriers to participation. Even though there may be greater understanding between LGB people with the same impairment, the network may be so small that it is ineffective for providing adequate choice for developing personal relationships (Shakespeare et al, 1996).

Despite resource difficulties, self help groups provide effective mutual support. Because women give greater value to building relationships and networking, lesbians have been far more successful than gay men (Shakespeare, 2000). Any future capacity building should take this into account. Another participant in our study commented:

'Most of us create our own community. I became disabled and was shunned by the lesbian community. They [other lesbians] have this fear that it [disability] might happen to them. It's essential [to see other LGB disabled people]. To be in a group where you don't have to explain yourself. I feel safer in the disability movement, we support each other. Maybe it's because we're focused on the practical issues and because we're used to challenging what's "normal".'

It is clear that whilst there is a shared community, it is one that people have had to seek out themselves, and form their own networks in. Isolation is seen as a real issue, particularly for those who have no access to other disabled people who are gay or lesbian. This contact is seen as essential. Isolation is also recognised as being a cause of both physical and mental health problems. Some other participants in our study told us:

'It always helps to have contact with someone who has had a similar experience, whatever that is, be it being a stranger in a foreign land or being gay and disabled.'

'I think it's immensely important [to have contact with other LGB disabled people], especially for those people who are physically isolated. You have all these desires, you see 'Queer as Folk' on the TV but you can't access it.'

E-mail has helped some people enormously in establishing their own networks, however people are quick to point out that this is not a solution for everybody and increased reliance on this medium can lead to heightening the exclusion of those without access to internet services. Another contributor explained:

'It's like when you find [other LGB disabled] people it's more important you make your own kind of community. There isn't like a community of people that meet up but you kind of, you do get to know people and e-mail's great because you e-mail each other. I think e-mail's done loads for disabled people and for LGB people in terms of putting people in contact.'

Most people feel that they have to make a choice between whether they associate with the LGB community or the disability community because there is rarely a shared community. However the majority feel that neither community really understands their identity and as such it can be hard for people to feel truly comfortable in either. Some people find that they switch between the two communities. For those who have

developed an impairment, as opposed to being born with it, identifying with the disability community might be something they don't wish to do. One of the contributors to our research felt that:

'There isn't really a disabled gay world or only very occasionally is it manifested, it's difficult for people really to sort of express both aspects, to feel welcome in both places.'

4.3 NATIONAL HEALTH SERVICE AND PROFESSIONAL RESPONSES

4.3.1 Prejudice

The health and social care sector has made little effort to take account of the life experiences of LGB disabled people. Contact with professionals is usually negative and the repercussions of "coming out" can lead to stressful conflict. Even where the treatment is the same for heterosexual and homosexual clients, satisfaction levels are lower for LGB people (O'Toole, 1996). Not only homophobic responses are given by staff, but also discouragement of sexual activity of any kind (Fine and Asch, 1988). In one of the focus groups, a disabled gay man told us:

'Unfortunately a few years ago I had a breakdown and I was sent to a psychotherapist. In the end I told her I was gay because I told her everything else. She kept asking whether I had a girlfriend and about having a family so I knew I had to tell her. Then she responded by saying that being gay had been my choice. It's not a choice. I'd hardly choose to make my life more difficult. I didn't feel I could go back after that so I ended up turning down the treatment even though I desperately needed it.'

There is consensus across all health professionals who participated in the research that there is likely to be some prejudice towards LGB people from those working in the NHS, including GP surgeries. Respondents comment that this group is likely to face prejudice for being either LGB or disabled and, in some case for both these 'reasons'. However all who responded said they have never witnessed any examples of this kind of discrimination. A nurse told us:

'I know that there is bigotry. I haven't come across it but I'm not naïve enough to think that it doesn't happen.'

'I don't want to think that the prejudice is there but it is – though it is changing I think.'

A number of participants explain that it is difficult to measure any form of prejudice in the NHS, particularly in GPs' services. One key reason for this is that prejudice is said to exist towards so many groups. For example, the receptionist we interviewed

commented that she and her colleagues spend so much time dealing with racial discrimination towards them that she has never given any thought to issues facing other groups, including LGB disabled people. The other obstacle to making an accurate assessment of the levels of prejudice, is that the majority of prejudicial behaviour is very subtle so that often it may not be possible to attribute it to a person's disability or sexuality. Another issue is that people have different interpretations of what constitutes prejudice and discrimination. It became clear, from talking to a number of respondents, that they do not consider gossip or joking about patients a form of prejudice. A nurse told us:

'People do talk about the different patients. We have someone who is a transvestite and he is a bit of a figure of fun with some of the receptionists. [They] sometimes go out the back and have a giggle. But it's because they're afraid...because they don't feel comfortable with what he was doing.'

4.3.2 Discrimination

Interviewees acknowledged that the health system does, in general, discriminate against disabled people in terms of access for some disabled groups being severely restricted. Health professionals tell accounts of local facilities that are fully or partly inaccessible to wheelchair users. One respondent comments that those with hearing impairments can face difficulties in accessing information and services due to the lack of interpreters.

There is less awareness of discrimination against people because of their sexual orientation although all respondents assume that there are pockets of such prejudice. It is noteworthy that whilst GPs, nurses and receptionists respectively say that there is no such prejudice amongst their peer colleagues, each group feels that prejudice towards LGB people may be more commonplace with those working in other roles in their surgery. A GP who we interviewed said:

'I can imagine that some people [in the Health Service] might be prejudiced. Some think that all gay people are promiscuous...some seem not to know that HIV can be transmitted through blood transfusions or whatever...it is not always sexually transmitted.'

Meanwhile, a surgery receptionist told us:

'The doctors in the practice are very strict Christians. You can sense that they might be against [LGB people]. I remember once picking up on a conversation where one of the GPs said that in the Bible it says that two male dogs don't go together, two male animals don't go together, don't find each other attractive. It was like he was saying that humans are in some way worse than animals...and that it shouldn't happen.'

However, whilst health professionals interviewed accepted that discrimination towards LGB disabled people exists in some areas of the NHS, the perception among them was that this generally does not impact upon the services people receive beyond, in some instances, access issues. A receptionist interviewed for our study told us:

'I'd never look at someone and treat them differently if I thought they were gay or lesbian. It just doesn't happen.'

Nevertheless, a couple of respondents said that they can imagine that a minority of nurses and GPs may treat LGB patients differently to non-LGB patients in that they may act 'over cautiously' in dealing with LGB patients for fear of contracting HIV. A nurse interviewed said:

'Talking from personal experience it wouldn't worry me but people might be extra cautious ...particularly given the bad press relating to AIDS. If you're a decent practice nurse you should always treat people as if they've got hepatitis B or AIDS ...the standard of care shouldn't be affected.'

4.3.3 Training and Guidance

Health and social care professionals need improved training and development, to dissuade them from their traditional and fundamentally pathological approach of "managing the problem". Too often, staff confuse protection, abuse, challenging and offending behaviour and the right to sexual expression (Brown and Thompson, 1997).

Doctors and other health professionals also need to improve communication with service users. It is also unhelpful to refer matters of sex back to parents or staff in residential homes, as individual concerns are not likely to be addressed. This leaves the service user isolated, resorting to gather whatever information they can from the media and their equally uninformed friends (Porter, 1987). A disabled lesbian in one of our focus groups told us:

'I was having a well woman check and I said to the practice nurse, I'd like you to show me how to examine my breasts and so she waved this leaflet – at a blind woman, you know, I'm obviously blind. So I asked her to show me and she was literally going poke, poke with her finger. It was like she was miles away. (What was making her uncomfortable?) The fact that I was blind and I'm a lesbian yeah, both, both counts. They're usually quite keen to show you how to do it.'

None of the participants had had any form of training or guidance in regard to LGB disabled people. A number commented that training to make staff aware of issues facing LGB disabled people would be helpful. One participant commented that this kind of training would be most needed outside of London where they assume homophobia is

more widespread and LGB people will consequently be less open about their sexuality. Another respondent said that the most effective form of training would be to have LGB disabled people giving talks to health professionals about their experiences and the experiences of other LGB disabled people.

One of the GPs consulted said he would like concise information on issues facing LGB disabled patients, preferably in leaflet instalments for GPs to dip into when they have a spare minute. He would like to see this backed up by an information directory being issued to every GP practice detailing issues facing, and services available to disabled LGB people from the NHS and other organisations.

One of the nurses interviewed said that whilst she does not think that training and guidance around LGB people should be introduced, she thinks that all people working in the NHS would benefit from training on treating and valuing people as individuals. A nurse interviewed for our study acknowledged:

'Some of the things that you've mentioned...I'd never thought of. It would be good to have some education about people's specific needs...to talk about their experience and raise issues that other people are not aware of. It's all about raising awareness of the issues people face.'

4.4 CONCLUSIONS

4.4.1 Summary

This study shows that LGB disabled people face extensive prejudice and discrimination. They are marginalised by society generally, whilst health and social care services – designed to provide objective support – systematically fail to meet needs and empower people. This has a significant impact on emotional, social and economic rights. This study, however, only touches the surface of the oppression faced by LGB disabled people. The main issues elucidated include:

- Society perceives disabled people to be asexual, leaving them vulnerable to abuse or being unfulfilled;
- Health and social care professionals focus on medical and functional support, failing to recognise personal and emotional needs;
- Sex education is wholly inadequate and fails to address issues of difference – both in terms of sexual orientation and implications of impairment;
- Guidance about safer sex is largely ignored by health and social care professionals working with disabled people;
- There is widespread homophobia in society and the disability movement and NHS both mirror such prejudice;

- Negative attitudes towards disability, echoed by body beautiful imagery, serve only to devalue disabled people within the LGB community.

4.4.2 Recommendations

This study has only touched the surface. While views expressed to us provide a useful insight, they are derived from a small scale qualitative research exercise. However, our findings reinforce the analysis of a comprehensive literature review. Clearly, there is a need for further research and consult on the experience and situation of LGB disabled people. Similar research into other dimensions of disability – age, race, gender and religious belief – would help shape the cross fertilization of issues that equality bodies might prioritise.

In order to develop the focus on multiple identity for equality and human rights, organisations involved in the disability and LGB fields need to think across the ‘labels’ and develop an integrated approach to diversity issues. Information, training, legal rights and organisational equality policies, access (in the broadest senses) and community support are all key ingredients which currently seem to be insufficient. Consequently, support to build the capacity of grass roots networking organisations is needed, particularly those which are bringing together LGB disabled people, and trying to tackle the problem of isolation.

Whether identity dimensions are managed separately or through an integrated commission, multiple discrimination needs to be challenged by effective mainstreamed legal enforcement. When public bodies have a duty to promote equality in a wide range of areas, not just race, they will need to address equality as a matrix instead of a set of silo issues. Likewise, diversity and corporate social responsibility will need to take account of links and tensions across the equality arena. This will be achieved if statutory bodies established to support such initiatives take an integral approach and work collaboratively.

Specific recommendations arising from this research include:

- British and Irish equality and human rights bodies should continue to undertake research and consultation, develop best practice and promote the rights of people with multiple identities;
- The Disability Rights Commission should work in partnership with Stonewall and self help groups, to encourage the Department of Health to combat negative attitudes about homosexuality and disability in general practice and other areas of NHS provision;
- The Joint Equality and Human Rights Forum, in conjunction with Stonewall and self help groups of LGB disabled people, should establish a “time limited” action-

focused Working Party to consider the findings of this study and practical measures that may be taken forward – diversity training and information resources aimed at health professionals;

- In taking forward its wide ranging agenda, the Disability Rights Commission should take into account issues pertinent to LGB people;
- In representing and supporting the interests of LGB people, Stonewall should take into account the needs and aspirations of disabled people; and,
- The Disability Rights Commission and Stonewall should undertake an awareness raising campaign within the LGB community, focusing on clubs and pubs meeting new access requirements that apply from 2004.

4.4.3 The Way Ahead

To sum up, people experience a multiplicity of identities. They identify with one more than others, depending on the particular occasion. It is a labyrinth of experience, tied up with similar features, contradictions and tensions. In responding to this rich diversity of individuality, human rights and equality bodies now have the opportunity to spearhead change across social and cultural boundaries. Ultimately, LGB disabled people deserve recognition. As one of our participants articulated:

‘It’s not just about ramps and Braille, it’s about being allowed to lead a full life and that includes your sexuality.’

In order to develop the focus on multiple identity for equality and human rights there is a consensus that all the different organisations need to start thinking across the ‘labels’ and develop an integrated approach to diversity issues. Moreover, if disabled people are to participate fully in society, they should not encounter institutional barriers or restraint of expression – free to “pull” as equal citizens.

NOTES

- 1 Stonewall culture fashioned the romantic struggle to break free of the closet. In essence, repressed in the closet, LGB people are liberated by the act of coming out (Seidman, 1998).

REFERENCES

- Barnes, C. (1991) *Disabled People in Britain and Discrimination*: Hurst and Co., London.
- Brown, H. & Thompson, D. (1997) *A minefield in a vacuum – the ethics of working with men with learning disabilities who have unacceptable or abusive sexual behaviours*: in Cambridge, P. – *How Far to Gay? The Politics of HIV in Learning Disability*: Disability & Society, Vol 12 (3), 427-53, Oxford.
- Cambridge, P. & McCarthy, M. (1997) *Developing and Implementing Sexuality Policy for a Learning Disability Provider Service*: Blackwell, Health & Social Care in the Community, Vol 5 (4), 227-36, London.
- Clare, E. (1999) *Disability, Queerness and Liberation*, 123-38, South End Press, Cambridge, MA.
- Cook, J.A. (2000) *Sexuality and People with Psychiatric Disabilities*: Sexuality & Disability, Vol 18 (3), 195-206, Oxford.
- Cooper, E. and Guillebaud, J. (1999) *Sexuality and Disability* Radcliffe Medical Press Ltd., Oxford.
- Corbett, J. and Barton, L. (1992) *A Struggle for Choice* Routledge, London.
- Davidson-Paine, C. & Corbett, J. (1995) *A Double Coming Out – Gay Men with Learning Disabilities* British Journal of Learning Disabilities, Vol 23, 147-51, London.
- Davies, D. (2000) *Sharing Our Stories, Empowering Our Lives – Don't Dis Me!* Disability & Sexuality, Vol 18 (3), 179-86, Oxford.
- Fine, M. & Asch, A. Eds. (1988) *Introduction: Beyond pedestals – Women with disabilities: Essays in psychology, culture, and politics*, 1– 37, Temple University Press, Philadelphia.
- Finger, A. (1992) *Forbidden fruit* New Internationalist, Vol 233, 9, London.
- Grundy, E., Ahlburg, D., Mohamed, A., Breeze, E. and Sloggett, A. Eds. (1999) *Disability in Great Britain – Results from the 1996/97 Disability Follow-up to the Family Resources Survey* Department of Social Security, Research Report No. 94, CDS, Leeds.

- Harley, D.A., Hall, M. and Savage, T.A. (2000) *Working With Gay and Lesbian Consumers With Disabilities – Helping Practitioners Understand Another Frontier of Diversity* Journal of Applied Rehabilitation Counseling, Vol. 31.1, 4-10.
- Hodges, A. & Hutter, D. (1974) *With Downcast Gays* Pomegranate Press, London.
- Hutchinson, D. and Tennyson, C. (1986) *Transition to Adulthood*: Further Education Unit, London.
- McCarthy, M. and Thompson, D. (1994) *Safer sex for people with learning difficulties*: In Craft A. (ed) *Practice Issues in Sexuality and Learning Disability*: Routledge, London.
- Morris, J. (1989) *Able Lives*: Women's Press, London.
- Morris, J. (1991) *Pride Against Prejudice*: Women's Press, London.
- Oliver, M. (1990) *The Politics of Disablement*: Macmillan, Basingstoke.
- O'Toole, C. J. (1996) *Disabled Lesbians: Challenging Monocultural Constructs*, Sexuality and Disability, Vol. 14, No. 3, 221-236.
- Porter, M. January (1987) *Sexuality and People with Physical Disabilities*, World Health Organisation.
- Seidman, S. (1998) *Are we all in the closet?*, European Journal of Cultural Studies, Vol. 1(2), 177-192.
- Shakespeare, T. (2000) *Disabled Sexuality – Toward Rights and Recognition*: Disability and Sexuality, Vol 18 (3), 159-66, Oxford.
- Shakespeare, T. Gillespie-Sells, K. & Davies, D. (1996) *The Sexual Politics of Disability*: Cassell, London.
- Stonewall & Mori (2002) *Profiles of Prejudice*: unpublished research conducted by Mori on behalf of Stonewall's Citizen 21 Project, London.
- Thompson, S.A., Bryson, M. and de Castell, S. (2001) *Prospects for Identity Formation for Lesbian, Gay, or Bisexual Persons with Developmental Disabilities*: International Journal of Disability, Development and Education, Vol. 48, No. 1, 53-65.
- Tilley, C.M. (1998) *Health Care for Women with Physical Disabilities: Literature Review*

and Theory: Sexuality and Disability, Vol. 16, No. 2, 87-102.

Tilley, C.M. (1996) *Sexuality in Women with Physical Disabilities: A Social Justice or Health Issue?*: *Sexuality and Disability*, Vol. 14, No. 2, 139-151.

Vernon, A. (1999) *The Dialectics of Multiple Identities and the Disabled People's Movement* *Disability and Society*, Vol. 14, No. 3, 385-398.

5 SITUATION, EXPERIENCE AND IDENTITY OF DISABLED WOMEN IN NORTHERN IRELAND

Norrie Breslin

5.1 INTRODUCTION

The Equality Commission conducted research on the situation, experience and identity of disabled women in Northern Ireland. The decision to examine this group was informed by a number of factors. Exploratory research conducted by the Equality Commission during early 2001 had indicated that disabled people in Northern Ireland had experienced difficulties in accessing health care services. Furthermore it is widely accepted that there is a dearth of disability related research in Northern Ireland and this project offered an opportunity to fill this gap.

The primary aim of this multiple identity project was to explore the identity of disabled women and provide a snapshot of issues faced by this group in an attempt to answer the question; 'How do disabled women in Northern Ireland define themselves?' The focus was to consider how disabled women understand and perceive their identity. This research also offered a valuable opportunity for disabled women in Northern Ireland to be given a voice to not only discuss issues around identity but also identify other issues of importance to them.

The research comprised a number of distinct elements. A literature review was conducted of research on disabled women in relation to equality and/or human rights issues. In addition an examination of existing quantitative datasets was undertaken in order to paint a profile of disabled women in Northern Ireland. Focus group discussions with disabled women and representatives of the health sector in Northern Ireland were undertaken.¹

5.2 LITERATURE REVIEW²

5.2.1 Introduction

The literature review considered the comparative social and economic status of disabled women as well as recording evidence of the ways disabled women have experienced and negotiated discriminatory processes. In addition the development of the concept of double discrimination is discussed. 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.

5.2.2 Developing Visibility of Disability and Women

The particular disadvantage experienced by disabled women remained largely unrecognised until the 1990s. 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.

A number of key events took place during the 1990's

- 1990 Experts Seminar of the UN on disabled women
- 1995 NGO Forum in conjunction with UN Women's Conference in Beijing
- 1997 International Leadership Forum for disabled women in Washington DC

All three of these events highlighted the need to address the following as key issues; education, employment, personal politics such as reproduction and sexuality and support mechanisms for the emerging voice of disabled women.

5.2.3 The Multiple Oppression of Disabled Women

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

Some writers suggest that the experiences of disabled women are not that dissimilar to women in general. Thus Lloyd (1992) argues 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" (210; emphasis in original). This leads her to suggest that the disadvantages attending disability and the female gender respectively compound each other (Hanna and Rogovsky, 1991). She argues that an analysis of the circumstances of disabled women should also examine the impact of sexist social attitudes and practices.

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" (3; emphasis in original).

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" (68).

5.2.4 The Socio-Economic Status of Disabled Women

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

5.2.5 Disability and Sexual Politics

Asch and Fine (1997) observe that disabled women are less likely than women who are 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" (241).

Their approach is supported by research in both Britain and North America, which identified a number of concerns for disabled women. These included;

- Opportunities to form romantic relationships
 - Need and opportunity for sexual activity
 - The relationship between self-esteem and socio-economic circumstances
 - Abusive relationships and
 - Barriers to adequate general and reproductive health care
- (Nosek, 1998).

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" (73). 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 are portrayed as defective women. They become subject to the prejudicial assumption that defective women don't have children.

5.2.6 Women, Feminism and the Social Model of Disability

Jenny Morris observes that as the majority of disabled people are women then disability is a women's issue, "yet the experience of disabled women has been largely absent from feminism's concerns and, with the disabled people's movement, has tended to be tacked on as a 'special interest'" (Morris, 1996; 1).

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.

Keith and Morris (1996) were critical of 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.

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

5.2.7 Conclusion

The evidence from research over the past 15 to 20 years may be a reflection in part of the interests of the researchers. However 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. The literature highlights the importance of exploring the intersection of gender and

disability. This exploration is critical for an understanding of the unique set of barriers and identity issues faced by disabled women.

5.3 SITUATION OF DISABLED WOMEN IN NORTHERN IRELAND

In the absence of an up to date survey of the nature and extent of disability key facts relating to disabled women in Northern Ireland have been drawn from a number of sources³ relating to labour market participation, higher and further education participation and a health and well being profile. In addition experiences of service provision have been examined through research conducted by the Equality Commission (GB).

5.3.1 Labour Market Participation

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

5.3.2 Higher Education Participation

Data collected by the Higher Education Statistics Agency show that overall 5% of all students enrolled to study full time in higher education institutions in the North of Ireland during the academic year 2001/02 were disabled. Disabled women (55%) showed higher participation rates than disabled men (45%) but lower than women who were not disabled (60%).

Analysis of further education statistics reveal that overall 7% of all students in full time courses of study in colleges of further education in Northern Ireland (academic year 2001/2002) were disabled. Participation rates for disabled women (49%) were lower

than those for disabled men (51%) but higher compared to women who were not disabled (45%).

5.3.3 Health and Social Wellbeing

Analysis of the Northern Ireland Health and Well Being Survey, 2001 shows that 28% of the adult population were disabled. There were proportionately more women disabled (29%) compared to men who were disabled (26%).

A set of questions called the General Health Questionnaire (GHQ12) was used to identify the possible existence of mental ill health such as depression among respondents. Overall 21% 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 compared to people not disabled (34%). Women (44%) generally were also more likely to have experienced a lot or a great deal of stress compared to men (34%).

5.3.4 Social Activities and Service Provision

The Equality Commission NI conducted research in early 2002 to examine the extent to which disabled people experience difficulties when using services or social facilities.

Notable gender differences include; 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 compared to men (13%). Men (42%) were also more likely to state that they had no difficulties doing any of these activities compared to 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.

The limited statistics available in Northern Ireland support the broader literature, which argues that disabled women are marginalised in social and economic terms compared to disabled men and women who are not disabled. The literature review identified a number of issues to be addressed in the focus groups. Perhaps the exploration of these issues may help to explain the exclusion of disabled women evident within these statistics.

5.4 EXPERIENCE AND IDENTITY

This section reflects a summary of the findings of the focus group discussions.

Individual focus groups with disabled women were facilitated by Equality 2000 (Dungannon and Armagh), STEER Mental Health (Derry) and the North West Forum for People With Disabilities (Derry). The focus group with health professionals was organised through an equality network within health and social services in Northern Ireland. Independent facilitators were arranged for all four of the group discussions.

Focus group participants included disabled women with a range of impairments and experiences. Some were mothers others were not, some were in long-term relationships whilst others were not. The majority were not employed in full time or part time paid work, whilst others were looking after the home, undertaking voluntary work and part time education.

5.4.1 Gender and Disability

As a starting point to the discussions disabled women 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. There was consensus that women are treated less favourably than men in terms of expectations and accessing services. 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. Additionally it was agreed 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 societal and environmental factors. Much of the discussion related to 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, *'side lined'* or *'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 as women and 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, saying 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'*.

A doctor who participated believes that attitudes to abortion need to be challenged as a step to changing negative attitudes to disabled people. 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.'*

5.4.2 Personal and Private Relationships

A number of trends emerged when participants were asked to talk about their experience of personal and private relationships. Many said that they had tried to hide or had 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 currently deny they had any impairment 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 did not attend segregated 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 that; *'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.

Health sector participants discussed the issue of young carers and one 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'*.

5.4.3 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 as 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 impacting on service provision, which needs 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. A number of women said that they found attending the health centre and/or hospital very stressful and anxious because of the long queues and negative attitudes and one woman consequently avoids seeking medical help.

A health sector 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 as *'the training had been delivered by a disabled person'*.

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

5.4.4 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 have children. 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 impairments.

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 felt 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.

Most of the participants believed 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.

There was general agreement among health sector participants that, *'prejudice is deep rooted, we can be professional but deep down we do not agree'*.

Participants from the health service agreed 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'*.

5.4.5 Impact on Personal Choices

Participants were asked 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 secure certain services such as routine cervical smear tests because facilities were inaccessible, and they have given up trying to avail of these services. 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 that, *'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 your illness'*. This woman felt that she has lost out on years of her life.

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'*.

5.4.6 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.

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.

5.4.7 Other Significant Issues for Disabled Women

Participants were asked if there were any other issues which they considered important. 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, *'it's very difficult to get the service and this is due to negative attitudes and lack of training and very poor awareness'*.

Participants from the health sector revealed 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.

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 a number of participants felt that disabled women have a role to play in for example 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

The doctor who participated relayed how she had treated a disabled woman the previous day and was prevented from providing the full range of services because of access problems. 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.

A few participants from the health sector said that their awareness of disability issues had been improved through general equality training specifically around the statutory duties placed by section 75 of the Northern Ireland Act, 1998. 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'*.

All of the disabled 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'*.

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.

5.5 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 in 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 compared to disabled men. However, disabled women were less likely to be in paid employment compared to disabled men and women who were not disabled. In addition disabled women were more likely to experience difficulties accessing certain services and social facilities compared to disabled men. Disabled women were 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 somewhat in-answerable 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. Those 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 is of benefit to the development of equality strategies in 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. Equality Impact Assessments⁴ undertaken as part of public authorities equality duty should advance 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.

NOTES

- 1 A total of four focus groups took place, three with 17 disabled women and one with 8 representatives of the health service.
- 2 A review of relevant literature was undertaken by Nick Acheson, University of Ulster.
- 3 It should be noted that all of the surveys quoted employed different wording within questionnaire items used to identify disabled people and consequently are not comparable. In addition small sample sizes have limited the extent of the analysis of the respective surveys.
- 4 In Northern Ireland public authorities are under a statutory duty to promote equality in terms of employment and service provision and consequently are compelled to produce an Equality Scheme to be approved by the Equality Commission NI. This duty has been placed on public authorities by Section 75 of the Northern Ireland Act, 1998.

REFERENCES

- Asch, A. Fine, Michelle (1997). *Nurturance, Sexuality and Women with Disabilities. The Disability Reader*. L. J. Davis (ed). New York, London, Routledge.
- Barnes, C. and Mercer, Geoff, Ed. (1996). *Exploring the Divide: Illness and Disability*. Leeds, The Disability Press.

Begum, N. (1992). "Disabled Women and the Feminist Agenda." *The Feminist Review* 40: 70 – 84.

Crow, L. (1996). Including All Our Lives: Renewing the Social Model of Disability. *Encounters with Strangers: Feminism and Disability*. J. Morris (ed). London, the Women's Press.

French, S. (1993). Disability, Impairment or Something in between. *Disabling Barriers – Enabling Environments*. John Swain, V. Finklestein Sally French, Mike Oliver (eds). London, Newbury Park, CA, Sage Publications.

Hanna, W. J., and Rogovsky, B. (1991). "Women with Disabilities: Two Handicaps Plus." *Disability, Handicap and Society* 6(1): 49 – 63.

International Leadership Forum for Women with Disabilities (1998) Final Report. New York, Rehabilitation International.

Keith, L. and J. Morris, (1996). Easy Targets: A Disability Rights Perspective on the 'Children as Carers' Debate. *Encounters with Strangers: Feminism and Disability*. J. Morris(ed). London, The Women's Press.

Lloyd, M. (1992). "Does She Boil Eggs?" *Disability and Society* 7(3): 207 – 223.

Lonsdale, S. (1990). *Women and Disability: the Experience of Physical Disability Among Women*. Basingstoke, Macmillan Education.

Martin, J., White, A., and Meltzer, H. (1989). *Disabled Adults: Services, Transport and Employment*. London, HMSO.

Morris, J. (1991). *Pride against Prejudice: A Personal Politics of Disability*. London, The Women's Press.

Morris, J., Ed. (1996). *Encounters with Strangers: Feminism and Disability*. London, The Women's Press.

Morris, J. (1996). Introduction. *Encounters with Strangers: Feminism and Disability*. J. Morris. London, The Women's Press.

Nosek, M. (1998). US National Study on Women with Disabilities. *International Leadership Forum for Women with Disabilities: Final Report*. B. Duncan and R. B.

Bieler. New York, Rehabilitation International.

Oliver, M. (1990). *The Politics of Disablement*, Macmillan.

Oliver, M. and C. Barnes (1998). *Disabled People and Social Policy: From Exclusion to Inclusion*. London and New York, Addison Wesley Longman.

Rousso, H. (undated). *Research on Women and Girls with Disabilities*.

Smith, M. (1990). *The Prevalence of Disability Among Adults in Northern Ireland*. Belfast, Policy Planning and Research Unit.

Thomas, C. (1997). "The Baby and the Bathwater: Disabled women and motherhood in social context." *Sociology of Health and Illness* 19(5): 622 – 643.

Thomas, C. (2001). Feminism and Disability: The Theoretical and Political Significance of the Personal and the Experiential. *Disability, Politics and the Struggle for Change*. L. Barton (ed). London, David Fulton Publishers.

Vernon, A. (1996). A Stranger in Many Camps: The experience of black and ethnic minority women. *Encounters with Strangers: Feminism and Disability*. J. Morris. London, The Women's Press.

6 LEARNING TO GROW UP: YOUNG LESBIAN, GAY AND BISEXUAL PEOPLE IN NORTHERN IRELAND

Christine Loudes

6.1 INTRODUCTION

This research presents an account of some experiences of young lesbians, gay and bisexual (LGB) people in Northern Ireland and specific issues they face in accessing health services and employment.¹ It highlights some aspects of multiple identities especially along the lines of sexual orientation, age and gender. It highlights how the interplay of several identities means that young LGB people have to face different issues from “straight” (i.e. heterosexual) young people (e.g. invisible identity, homophobic bullying or victimisation at school) or older LGB people (e.g. absence of venues to meet other young lesbians and bisexual women or invisibility of teenage gay culture). It illustrates that identities are not necessarily obvious to another individual (as far as sexual orientation is concerned) but that young LGB people have to go through a process of self-identification called “coming out” which is difficult and sometimes followed by rejection.

The information presented in this report was collected through three focus groups with young LGB people,² one with health service providers³ and three interviews of young LGB people. The report begins by defining the terms of the research. The literature review, in the second part, highlights some issues, which are discussed further in the research and are important to the concept of multiple identities applied to young LGB. The third part articulates differences faced by young LGB people using statistics, relevant data, information on young lesbian’s identity and issues that young people discussed in focus groups and interviews. This part includes their experience of the health care system and some of employment. The report ends with a list of recommendations to the Government; health services providers and human rights institutions in Northern Ireland. These recommendations are based on the outcomes of the focus groups, national legislation and international obligations that the UK has signed up to.

6.2 DEFINITION OF THE TERMS

6.2.1 Lesbians, gay and bisexual identity

Language is important when dealing with people’s experience. There are words and terms that have a particular resonance for people. The following are the words used by LGB people to define themselves.⁴

A lesbian is defined as “a woman who is sexually and emotionally attracted to women. (Many lesbians prefer to be called lesbian rather than gay, queer or homosexual because it reflects their separate experience.)” A gay person is “a man or woman who is sexually and emotionally attracted to people of the same sex. (Many gay men prefer to be called ‘gay’ rather than homosexual).” A bisexual person is “a man or woman who is sexually and emotionally attracted to people of either sex.” In the LGB culture, the term queer is

employed as “a term primarily for gay men that is being reclaimed and some lesbians feel comfortable using it.” The term is also used in “queer theory” which explores how gender and sexual identities have been defined by representations (e.g. through language and culture). “[Queer theory] assumes that representations pre-exist and define, as well as complicate and disrupt, sexual identity.”(Hedges, 1997) Queer theory rejects the identity-based gay and lesbian criticisms of the 70s and 80s and highlights that this identity is not reflecting the reality of people’s experience but is a constructed representation.

6.2.2 Youth

Whilst the definition of children in the United Nations (UN) Convention of the Rights of the Child concerns people below 18 years of age, the definition commonly referred to in Northern Ireland when talking about “youth” is that used by the Department of Education. In its youth service policy, the Department has defined “youth” as those aged between 4 and 25 years of age (Department of Education of Northern Ireland, 1999). For some voluntary organisations offering services to young people, the term “youth” has been defined in a more restricted way as including people between the age of 16 and 25 years of age.⁵ At international level, the World Health Organisation has defined young people as those between the age of 10 and 24 (WHO, 1997). Whilst there are divergences as to the minimal age of “youth”, there appears to be an agreement that the concept of young people includes people over the age of 18 and is commonly understood as people up to 25.

From a sociological point of view, the notion of youth is understood as “people of a certain age, between childhood and adulthood, who form a significant social group, but it is difficult to define this age group precisely”(Frith, 1984). The extension of the notion of youth to people of legal majority can be explained by delays for young people in accessing the job market and becoming truly independent from their parents. “Youth”, in other words, describes aspects of people’s social position which are an effect of their biological age but not completely determined by it.” (Frith, 1984). Young people, as a group need protection because they are disempowered in our society (YouthAction Northern Ireland, 2002).

An important aspect of youth is the significance of peer groups, “peer groups are so taken for granted by sociologists that it is sometimes easy to forget that references to youth culture are usually references to people of the same age doing things in groups” (Frith, 1984). In the case of young LGB people, groups make an essential contribution to developing, accepting and discussing their identity.

This report examines the interplay of the numerous identities of young LGB people (i.e. sexual orientation, age, gender) and resulting issues (i.e. invisibility, violence, prejudice) facing them in Northern Ireland. As highlighted later, sexual orientation and age are not

the only factors of identification; religious backgrounds, gender, class, place of living are also determining factors in the identification of young LGB people.

6.3 LITERATURE REVIEW

To date, there is little research which looks specifically at identities, needs and rights of young LGB people in Northern Ireland.⁶ Usually, issues related to young LGB people have been dealt within research looking at LGB issues generally (Feenan et al, 2001 & Quiery, M., 2002). Several issues arise from the literature focusing on young LGB people and health within and outside of Northern Ireland. The recurrent issues are the invisibility of young LGB people; the lack of relevant sex education and access to tailored sexual health services; the high number of suicides, drug abuse and self-harm amongst young LGB people and mental health issues, and finally, the denial of human rights for young LGB people.

6.3.1 Invisibility of young lesbians, gay and bisexual people

The constant assumption of heterosexuality renders gay and lesbian people, youth in particular, invisible and seemingly non-existent. LGB youth are usually not seen or portrayed in society, and especially not in schools and classrooms. The lack of qualitative as well as quantitative data available contributes to rendering young LGB people invisible.⁷ Hence, there is little reference to the sexual orientation of young people when researching the needs of young people. The lack of research is also evident in other areas of equality legislation (e.g. minority ethnic groups) and illustrates the social invisibility in mainstream society of certain groups and a widespread social devaluation of LGB people.

Young LGB people have limited opportunities of getting information outside LGB organisations, phone-lines, internet and specialised magazines.⁸ There are several websites designed for young LGB people. They provide information and support and contribute to sharing experiences especially on the coming out process. These websites and phone-lines are crucial as they are the first port of call for young LGB people looking for information.

There is a lack of research in the area of the interplay between sexual orientation and gender. It is only recently that the needs of lesbians and bisexual women have been documented in Northern Ireland (Quiery, 2002). A consequence of the lack of information is that issues that are specific to lesbians and bisexual women are not addressed. A recent report stresses that “as a result of the impact of HIV and AIDS on the male community, the health needs of lesbian and bisexual women had been largely overlooked” (Quiery, 2002). As outlined by the findings in this report and the focus group with young lesbians and bisexual women, marginalisation and a sense of isolation appear to be even greater amongst young lesbians and bisexual women than the

experience of young gay-bisexual men. This is due to the invisibility of lesbians within the gay community. Outside of Northern Ireland, lesbian invisibility is also underlined in the ILGA Report (ILGA-Europe, 2000). This invisibility exists in several countries in Europe and results in a greater isolation and marginalisation along the lines of gender.

Research on the specific needs of bisexual people – beyond the needs for their sexual orientation to be protected – is limited. However, this should not hide the fact that young bisexual people might have particular needs and identities that are not reflected in the “gay” culture. Further, bisexual people sometimes meet disapproval from the gay and lesbian community who have mobilised around their sexual orientation and used identity-based politics. “Bisexuality, for example, might be viewed as merely a signpost on the road to a more “complete” gay identity, or a cop-out-a refusal of self-knowledge and political commitment” (Hedges, 1997). However, there are moves at European level to promote rights of bisexual people which are initiated by the International Lesbian and Gay Association (ILGA-Europe).

6.3.2 Sex education and sexual health

In Northern Ireland, young LGB people are not provided with sex education at school that reflects their sexual orientation (GLYNI, 2001). The hetero-centred approach to sex education at school reinforces their invisibility.⁹ Further, sex education is often provided during religious education classes, which does not facilitate exploration of LGB issues given the ethos of churches in relation to homosexuality (Health Promotion Agency, 1996).

In relation to sexual health, issues affecting young LGB people have been highlighted in recent research (Health Promotion Department & Westcare Foyle Friend, 2001). Young LGB people expressed concern around the lack of information available on sexual health. They also pointed out that most information available is male-oriented and does not meet the needs of young lesbians and bisexual women. The issue of accessibility to protection against STDs for women (dental dams)¹⁰ was raised in the focus groups and interviews.

6.3.3 Suicide, self-harm, drug abuse and mental health issues

The rate of suicide among young lesbians, gay and bisexual people in the UK appears to be much higher than the average for young people (ILGA-Europe, 2000). It is linked to the constant victimisation, bullying, isolation, marginalisation and harassment to which young people are subjected because of their perceived different sexual orientation. Research in the United States have linked victimisation on sexual orientation with suicide attempt (Noell, 2001). The study, conducted amongst a population of homeless adolescents, highlights the association between sexual orientation, suicidal attempt and drug use. “The homeless youths who are gay-lesbian-bisexual clearly are a troubled group with high rates of depression and injection of drug use” (Noell, 2001). In

England, a study in 1996 presented similar findings (Rivers, 1996). Preliminary findings from forthcoming research looking at the education of young people, highlights the fact that these issues are affecting young LGB people in Northern Ireland too. Amongst 362 young people under 25 years of age,¹¹ 29% had attempted suicide, 26% self harmed, 24% were medicated for depression, 21% had an eating disorder (research by Youthnet, YouthAction Northern Ireland, GLYNI, Foyle Friends, the Rainbow project & VSB). These figures are quite alarming but coincide with findings in the US and England and they suggest that measures should be taken by health services to address the lack of structures of support for young LGB people.

6.3.4 Denial of human rights

Like other LGB people, young people are denied some basic human rights. The literature dealing with rights of LGB people has highlighted issues faced by young people (ILGA-Europe, 2000 & Feenan et al, 2001). These include bullying, discriminations against young LGB people, issues in relation to breach of confidentiality and lack of sex education tailored to the needs of LGB young people.

Recently, violation of the rights of young LGB people was mentioned in the Concluding Observations to the UK of the Committee of the Rights of the Child. When considering adolescent's health in the UK, the Committee expressed concern around the lack for "homosexual young people" of "access to appropriate information, support and necessary protection to live their sexual orientation." The Committee was alarmed by the rising incidence of STDs¹² among young people. Further, issues of access to mental health services for young people have also been highlighted in the Concluding Observations of the Committee of the Rights of the Child. The Committee has recommended that the UK "take all necessary measures to strengthen its mental health and counselling services, ensuring that these are accessible and sensitive to adolescent, and undertake studies on the causes and backgrounds of suicides."

Most issues presented in the literature review have been reflected in the focus groups discussions and interviews. Those findings are presented below.

6.4 IDENTITY AND EXPERIENCE OF YOUNG LGB

Issues considered below have surfaced within the focus group discussions and interviews. Whilst some issues around LGB identities were mentioned during focus groups, most of the discussion centred around the experiences of young LGB people in society in general, school, health services and, to a lesser extent, employment. This part illustrates that personal identity develops through an interactive process between the individual and his or her environment. When asked to talk about themselves young LGB people mentioned issues related to how they define themselves but essentially focused on the impact on their lives of the resistance of their environment (school and health service) to accept their identity.

6.4.1 Identity

Several aspects of youth identity were expressed during the focus groups. The most important one of these was the process of “coming out.” Other issues linked to identity were mentioned including internalised homophobia, multiple identities of participants and the invisibility of gay teen culture.

Coming out

“Coming out is the term used by lesbians, gay men and bisexuals to describe their experience of self discovery, self-acceptance, openness and honesty about their sexual orientation and their decision to share this with others when and how they choose.”¹³ It is a delicate and long process of affirmation of one’s identity which has been described as a succession of stages by theories of identity development (Beatty, 1999). Most young people start the process of coming out during adolescence which adds to the confusion inherent to adolescence. As outlined by a participant in the focus groups: *‘Young people have to face the same difficulties as other teenagers and on top of that the issue of coming out.’* Another participant reported that: *‘when you are gay, you have to mature more quickly; you have to learn to grow up.’*

The coming out process results in the person identifying as LGB personally and publicly. Because of the social pressure, some LGB people prefer to stay “in the closet.” This term describes lesbians, gay men and bisexual people who are not open about their sexual orientation. Coming out usually happens first within the gay community where young people find support and understanding. Many young people in the focus groups had not come out to their parents but found strength in regular meetings with other young LGB people.

Fear of exclusion means that coming out to one’s family or friends is an extremely difficult step. Anxiety was expressed on several occasions in the focus groups and several of the young people had not come out to their family. *‘I worry, will my parents kick me out when they find out?’* Coming out requires lots of courage from young people and it is a difficult process. *‘I am not sure how my mum would take it if I told her. I’d prefer if she approached me on the issue.’* Another participant highlighted the difficulty with coming out at a young age. *‘It is very hard to tell them that you are gay. Once you tell them, they think that you are confused and try to talk you out of it.’*

Some participants mentioned the fact that when they came out, their parents and grand parents or other relatives expressed moral judgements on them being gay and said that “they will go to hell.” *‘My granny is the only one who has a problem with it. She thinks the devil is inside us and that it is not our fault if we are gay.’* Several participants have not come out to their family for fear of being judged or rejected. Other young people reported that despite their religious convictions, their parents were quite supportive. *‘My*

mum knows about it and she accepts it because I am her son... but she keeps being worried about me going to Belfast.'

Participants also mentioned the fact that they thought there was not enough support for parents of young LGB people, especially in rural areas. This point stresses the fact that coming out is a process affecting the family as a whole beyond the young LGB person. It was mentioned that the Parent Advice Centre (PAC) is working with GLYNI (Gay Lesbian Youth Northern Ireland) on this issue and that an information leaflet has been recently published for parents of young LGB people (Eastern Health & Social Services Board, 2001). Research has recommended that family therapy can be useful in helping the connection to be maintained between young people and their families (Lasala, 2000).

Coming out to friends is another difficult process. *'I've told a few of my friends. Most of them were fine with it. But my best friend thought I was joking and she told other people... You really have to be careful who you tell.'*

Participants mentioned the fact that the culture in Northern Ireland society was not conducive to coming out for young people. *'It is a political and religious thing...people have strict ideas around sexuality.'* Some people explained that they did not come out for fear of being stigmatised. *'I want to be known as me not just the lesbian', 'You always have to talk about your sexual identity...it's hard to have a bit of normality, just like everybody else.'*

In the focus group with Out and About,¹⁴ women talked about domestic violence within lesbian relationships and most seemed to feel that lesbians rarely reported domestic incidents because they felt uncomfortable about disclosing their sexual orientation to the police or health care workers. In several focus groups, the issue of revealing sexual orientation when dealing with the police on homophobic assaults was mentioned. Many young people have difficulties with coming out to the police and felt that they are not taken seriously when they do reveal their sexual orientation.

Internalised homophobia

This term is understood as "the fear and self-hate of one's own homosexuality or bisexuality that occurs for many gay and lesbian individuals who have learned negative ideas about homosexuality throughout childhood. Once gay and lesbian youth realise that they belong to a group of people that is often despised and rejected in our society, many internalise and incorporate the stigmatisation of homosexuality and fear or hate themselves."¹⁵ During the focus groups, several young people expressed positively their sexual identity; however on some occasions they referred to previous thoughts they had such as "I wish I was not gay." This illustrates that some young people, when isolated, internalise homophobia. Support groups and participation in the (Gay) Pride events, celebrating gay culture, are important in overcoming this internalised homophobia.

Multiple identities

Multiple identities are central to the lives of young LGB people in Northern Ireland as mentioned during the focus groups. The experiences of young LGB vary according to additional identities to sexual orientation and age. Hence their gender and the place where they live are significant. In relation to rural areas, young people feel a lack of support and a greater sense of isolation and invisibility because access to the gay scene is limited. The gay scene in Northern Ireland is small and is concentrated in cities; there is no support or meeting point for people who are living in the countryside. Further, in rural areas young people feel an added pressure as it is harder to keep anonymity. As outlined throughout this report there are issues around gender resulting in lack of support, invisibility and few meeting places for young lesbians and bisexual women. Further issues were mentioned for lesbians and bisexual girls in custody (i.e. difficulty in accessing dental dams and ignorance from staff). There are without doubts further issues to be explored around ethnicity and disability but these were not mentioned in the focus groups.

Invisibility of LGB teen culture

Young LGB people mentioned the invisibility of LGB youth culture. *'Gay teenage culture exists but it is not visible. You have to make an effort to find it.'* They felt that the media have a role to play (this was expressed also during the focus group with health service providers) but that they did not show any role models for young LGB people.

6.4.2 Experience of young LGB people

The experience of young LGB people in Northern Ireland is difficult and often painful as testified by some of the focus groups' participants. Young people face institutionalised heterosexism, isolation and violence. All these issues are intertwined and very often one is the cause of another. Internalised homophobia is often the consequence of exposure of young LGB to violence and/or institutionalised heterosexism combined with a sense of isolation reinforced by the lack of role model. Invisibility, sense of isolation and exclusion in turn impact on the (mental or physical) well-being of young LGB people and can drive some of them to suicide.

Institutionalised Heterosexism

This term is understood as "a system that has embedded within it unfair discrimination against, and the oppression of lesbians, gay men and bisexuals. It is often a subtle form of oppression which reinforces realities of silence and invisibility for gay and lesbian youth."¹⁶ This phenomenon is a form of cultural imperialism from the heterosexual majority. It is apparent in several aspects in the lives of LGB young people and is also culturally embedded in the media, language, educational system and politics.

Participants in all focus groups (young people and health services providers) and interviews mentioned the particularly oppressive nature of Northern Ireland society in relation to LGB life style and the fact that this moral disapproval is apparent at every stage of the life of a young person and especially at school. When asked about their particular experience, one young person said that *'there is nothing special about being gay but there are issues around being gay in Northern Ireland because of a social and religious stigmatisation of homosexuality. The strong influence of the church in education is impeding an open discussion on LGB issues.'* At school, a strong religious ethos often prevails which is not conducive to discussing issues such as sexual orientation and reinforce the invisibility of young LGB people. Experiences mentioned in the focus groups illustrate that this moral approach is also present amongst medical staff. Institutionalised heterosexism is also seen as the reason for the lack of funding for the voluntary organisations offering support and information to young LGB people.

Isolation

When asked to describe the commonality among LGB youth, one participant said *'one common experience of young LGBs is the isolation.'* This isolation is manifested in the lack of support and understanding around young LGB people and the stress related to coming out. *'Isolation ties in with the pressure, with not being able to come out.'* *'My parents are fine; we just don't talk about it.'* *'My parents are embarrassed and ashamed.'*

To overcome this isolation, youth groups are very important. Everyone in a focus group with Out and About (Youth Action Northern Ireland) agreed that they gained a great deal of support from meeting as a group twice a month. To their knowledge they are the only young lesbian support group in Northern Ireland. They felt there was a strong need for more support and information. Several of the young women talked about the fact that they had no one to talk to about their sexual orientation when they were younger. One young woman said that she would often ring the Samaritans just to be able to talk about her feelings openly. Others talked about using the internet to find out more about being lesbian.

Violence

Young LGB people are exposed to a high level of violence. This violence happens at school and in the street when they are perceived as being gay. Several participants referred to their experience of stigmatisation, name calling and bullying at school. *'I came out when I was 14 and I'm always being labelled as "The lesbian" at school.'* During the focus group with service providers one participant said: *'On our boy's playgrounds, they know that the worst thing that they can be called is gay. Five and six year olds are saying it without having any idea of what it means. They just know that it is a derogatory term.'* One young woman reported *'when I was 14 or 15, I got kicked and*

pushed every day coming home from school.' Another participant mentioned his experience of seven years of bullying. There was no support to deal with homophobic bullying; it was not even acknowledged that this was happening in the school. Many young people felt that schools do not know how to deal with bullying and even less with homophobic bullying. The issue at school is not limited to bullying by peers; some young people reported victimisation from their teachers. *'Teachers are the ones who gave me hassle'* and *'Teachers would gossip about me.'* One solution is located in education on equality and diversity. *'Diversity needs to be taught at a young age...things shouldn't just be looked at in text book terms.'*

One young woman talked about being the victim of a homophobic attack during which she was badly beaten. When she got home her mother said that this would always happen to her because of the "lifestyle" she was leading. Participants in focus groups reported that a high number of young people have been attacked coming out of gay night clubs and have been victims of homophobic assaults.¹⁷

6.4.3 Experience in the health care system

By way of introduction to the delicate relationship between LGB issues and health care system, it is important to remember that up until a decade ago the World Health Organisation classified homosexuality as a mental health disease. This position resulted in an ambiguous position between the health system and LGB people.

Prejudices in relation to health services.

Whilst a few young LGB people were very open and confident in their GPs and had positive experiences, several of them recounted that their GPs were judgmental about their sexual orientation. One young woman reported that her doctor said to her that "gay people go to hell." He "outed" her to her family and wanted to book her in to see a psychiatrist. *'I felt guilty to be gay and depressed. So I went to see another doctor. But he was also making comments and I was still depressed.'* These attitudes inspire some feelings of anger, mistrust and hurt amongst young people.

Health service providers send out an ambiguous message to LGB people. On the one hand, they offer non-judgmental advice on sexual health to young LGB people in GUM Clinics (Genito-Urinary Medicine) on the other, they refuse to take blood from gay men. Consequently, young LGB people feel that they are either invisible or stigmatised by health professionals. *'Blood transfusion services do not take blood from gay men and this contributes to stigmatising gay men and marking lesbians, gay and bisexual issues. Gay men are still perceived as carrying HIV.'* The Terence Higgins Trust, a charity working on education on HIV and AIDs, discussed guidelines on blood donations with the National Blood Authority and stated that "current guidelines, while contentious and sometimes poorly expressed, should be abided by and regularly re-examined." However

it does also call for greater clarity about the grounds for exclusion.¹⁸ The stigmatisation of young LGB is centred on HIV and the use of language. One nurse reported that: *'the language used in the health care system shows the stigmatisation of LGB. HIV patients are called AIDS patients and medical staff wonder if they are gay.'* This stigmatisation combined with a sense of isolation and invisibility drive young people to hide their sexual orientation when they access the health care system.

Breach of confidentiality

There is an assumption that everyone is heterosexual and when it is otherwise, young people have to identify themselves as being gay/lesbian/bisexual to access health services, especially sexual health. Health professionals in the focus group felt that the system is built in a way that forces gay, lesbian and bisexual people to come out. This is not expected of young heterosexual people. One young person said *'doctors assume you are straight, you have to out yourself.'*

Focus groups' participants mentioned a negative experience with their GP in relation to respect of their privacy. In some cases, GPs threatened to or did "out" young people to their family. The issue of forced outing of young people should be considered with care. It puts young people into a position of vulnerability and fear of losing familial support (as explained in section 3.1.1). *'I spoke to the family doctor about the fact that I am gay and then he spoke to my mum. He broke the confidentiality and "outed" me.'* It is also a breach of the young person's human right to private life and confidentiality which is protected by human rights law (Article 8 of the European Convention of Human Rights).

Lack of structures of support for young LGB people

Because of the violence, social disapproval, isolation and discrimination they experience, young LGB people are more subject to depression, anxiety and poor mental health than their heterosexual peers. *'Mental health issues are linked with coming out and the stigma attached to being gay in particular in the Northern Irish society.'* In the focus group with young lesbians and bisexual women, participants talked about the prevalence of mental health problems among lesbians and the lack of support available. They felt that mental health problems were linked to lack of acceptance, the pressures of having to "hide" one's sexual orientation and the pressures resulting from being openly lesbian. *'[Having to hide one's sexual orientation] leads to lies and guilt and stress.'* Both, the process of coming out in a society which devaluates LGB lifestyle or the need to hide one's sexual orientation are factors impacting negatively on the emotional and mental well-being of young LGB people.

Sexual health

Sexual health is an issue that was frequently mentioned in the focus groups. The lack of information and tailored services to deal with the needs of LGB young people is a big issue. *'Things that are important to us are never explained'* and *'There isn't enough information about STDs [sexually transmitted diseases].'* As illustrated by recent research (Health Promotion Department & Westcare Foyle Friend, 2001), the awareness level amongst young LGB on sexual health and STDs is limited: *'95% of people on the gay scene aren't aware of sexual health.'* This can be due to the fact that *'It's awkward to ask about sexual health'* but also the fact that LGB young people are made invisible by a system that caters mainly for heterosexual people.

This issue outlines the gender dimension of the study as young lesbians and bisexual women felt that issues on sexual health for LGB people were concentrated around male sexual orientation. Issues specific to young lesbians and bisexual women are often overlooked. Participants in several focus groups mentioned that the needs of young lesbians and bisexual women are not catered for. Hence, dental dams are not freely available whereas young gay men can access condoms freely.

6.4.4 Experience at work

Amongst young people who took part in the focus groups and interview, three persons had been training or working as nurses. Their experiences of working in the health system differed as some worked in private nursing and some work in a public authority. However, experiences reported by these young people did not draw a positive picture of the conditions of work in the health system. One young person described how he was discriminated against at work and victimised by his employer. This victimisation led to the resignation of the person. The victimisation went even beyond the loss of the job when he discovered that no solicitor wanted to take his case against his employer for constructive dismissal.

One young man outlined that he felt there was a difference between the treatment of people working in the public sector where some protections were put in place to address discrimination, bullying and victimisation in the workplace, and in the private sector where these protections are not available. Despite this he decided not to come out because he did not want to be stigmatised at work and talked about behind his back.

A young lesbian explained her reasons for not coming out at work *'I'm not out to work colleagues because I work in an all male environment....male attitudes to lesbians... they don't understand, they feel threatened or treat it as a sexual fantasy.'*

Similar issues have been outlined in a recent report on young lesbians and bisexual women (YouthAction Northern Ireland, 2002). More generally, many young LGB people still feel that they have to hide some aspect of their identity in the workplace (even

where legal mechanisms are in place) because they feel that their sexual orientation will be a factor of isolation and alienation from their colleagues.

6.4.5 Conclusion

This research highlights that the experience of young LGB people in Northern Ireland is characterised by four elements invisibility, exclusion and denial of human rights; isolation and diversity amongst young LGB people. The invisibility of young LGB people is characterised by the fact that their experience is rarely documented and that the gay teenage culture is not represented in mainstream culture. When they decide to come out, young LGB people are often exposed to homophobia, bullying and victimisation. If they decide to delay the process of coming out, young people tend to find themselves isolated in a culture promoting a heterosexual life style. The focus groups and literature review showed that young LGB people encounter obstacles that heterosexual young people might not face in accessing health services (e.g. prejudice and lack of properly tailored services) and educational services (e.g. homophobic bullying and victimisation). Further, young LGB people are exposed to denial and/or negative perceptions of their identity at a period where they are in a vulnerable position due to their age. Those difficulties need to be further documented, researched and taken on board by service providers and decision-makers.

The focus group discussions also highlighted the diversity amongst young LGB people living in Northern Ireland. Gender is an important factor in the identification of young lesbians and bisexual women. The focus group with young lesbians and bisexual women confirmed some of the literature findings around the invisibility of lesbians and bisexual women. This invisibility and sense of isolation is increased for young lesbians who have few places to meet and to discuss issues related to their experiences. Another important factor mentioned during the focus groups was the place of living. Participants highlighted the sense of isolation faced by young LGB people living in rural areas. Within the group chosen for the study there are people with multiple identities, which are defined along the lines of sexual orientation, age, gender, place of living. Other identification should be considered in further research such as class, disability and ethnicity.

6.5 RECOMMENDATIONS FOR CHANGE

Several recommendations have been suggested in focus groups (by health professional and young LGB people). Other measures are the consequence of the implementation of domestic or international law. Finally, some recommendations are addressed to the Human Rights Commission and the Equality Commission in Northern Ireland.

6.5.1 Recommendations in health service provision

This research highlights that the health needs of young LGB people are not exclusively an issue for health professionals. Thus, a holistic approach to health care (involving a co-operation between schools, the social care and the medical professionals) should be promoted to deal with the needs of young LGB people. This approach should consider the cause of health problems and define health and social services in an environment conducive to dealing with them. In this process education on health, especially sexual health, information provision and support structures should be provided for young LGB people.

- There is a need for continuous training of the medical profession to recognise societal evolution. This recommendation was suggested during the focus groups by both services providers and young LGB people. Both agreed that the needs of young LGB people are not adequately met at present and that training would be a first step in achieving this. However, while young lesbians, gay and bisexual people thought that a specialised training should be given, the health professionals thought that it should be mainstreamed into training on the needs of young people. For an effective implementation of the statutory duty to equality of opportunity set in Section 75 of the Northern Ireland Act 1998, medical staff should be trained in the needs of young LGB people and address the prejudices and stereotyping facing young LGB people.
- Participants in the focus groups suggested that GPs and health professionals should create a friendly environment for young LGB people that is conducive to the process of coming out. For instance, by placing leaflets on sex education in GPs surgeries and pharmacies for consultation by young people. Posters on LGB issues and sex education placed in GP's surgeries would make it easier for young LGB people to engage with their doctors. These posters and leaflets are available from organisations such as the Rainbow project.¹⁹ In addition, a list of GPs that are LGB friendly could be compiled for the use of young LGB people.
- In accordance with international obligations, health and social services providers should consider setting up tailored mental health mechanisms to deal with the needs of young LGB people to overcome the stress of coming out, of victimisation, of bullying and of discriminations.
- Schools lead by the department of education should play a proactive role in providing information on LGB issues (for instance sex education) and putting in place structures to ensure that homophobic bullying is effectively addressed.
- Given the important role played by LGB organisations in providing information and support to young LGB people, those should be properly funded. In addition, health

services providers should increase/consider partnership work with LGB organisations.

- The Government should implement its international obligations, which recommended putting in place structures to “provide adequate information and support to homosexual [...] young people.” (*Concluding Observations of the Committee of the Rights of the Child: United Kingdom of Great Britain and Northern Ireland* 31st Session, 833rd, paragraph 42). This implies a need for information and outreach on sexual health and mental health issue.
- In the implementation of Section 75 of the Northern Ireland Act 1998²⁰ and the implementation of their Equality schemes, health and social service providers need to avoid the trap of considering the nine groups specified in Section 75 in isolation. This research illustrates that it is important to examine the needs of people with multiple identities. This is the case for young LGB people who are placed at the intersection of several categories such as sexual orientation, age, gender, disability and potentially ethnic minority. The “one size fits all” approach that has prevailed in many areas of health should be reconsidered to respond to the needs of young LGB people.
- The absence of statistics on the number of young LGB people and research into their needs should be remedied by the engagement of public authorities in financing and conducting the gathering of statistics. The Concluding Observations of the Committee of the Rights of the Child noted that “the Committee is still concerned with the absence of a nation-wide mechanism to collect and analyse data on the areas covered by the Convention.” This should include young LGB people.
- The right to privacy is an internationally recognised right (e.g. Article 8 of the European Convention on Human Rights) and Article 16 of the Convention on the Rights of the Child is applicable to young people. Consequently, it is the duty of the State to introduce proper safeguards to ensure that confidentiality is respected between medical staff and the young person. This action should be instigated by the Department of Health and Social Services and Public Safety, the British Medical Association for GPs and the different health Trusts and Boards so that there is uniformity in implementation. Further, people under 16 years of age are able to consent to medical treatment without parental consent according to the *Gillick* principle.²¹
- The implementation of the European Framework Directive on Equal Treatment in Employment and Occupation (Directive 2000/78/EC) should not be reduced to measures for the elimination of discrimination in employment but extended to include provisions dealing with access to goods and services, including health services.

- The Human Rights Commission and the Equality Commission should ensure protection of the rights of people with multiple identities in the forthcoming Single Equality Bill and the Bill of Rights.²²
- The Human Rights Commission should take a case in its own name under the Human Rights Act, seeking to establish the scope of Article 8 in relation to confidentiality particularly with reference to the rights to privacy for young LGB people. This would test the *Gillick* principle in light of the Human Rights Act and would establish clearly the law in this area. It would ensure that the privacy of young LGB people is protected when dealing with medical and educational staff.

6.5.2 Recommendations in employment

- Statutory bodies should enforce the obligation of equality of opportunity contained in Section 75 of Northern Ireland Act 1998, through training of existing staff, reiteration of commitment to equality duty when advertising vacancies and place advertisements in gay, lesbian newsletters and magazines.
- Employers should ensure that proper mechanisms are put in place to avoid any victimisation, bullying or harassment. This should be provided for in the Single Equality Bill.

NOTES

- 1 I would like to thank the following organisations for their contributions to the research: Brook Clinic Belfast, Central Services Agency, Committee for the Administration of Justice, Eastern Health and Social Services Board, Dunluce Health Centre, Gay Lesbian Youth Northern Ireland, Green Park Health and Social Services Trust, Family Planning Association, Foyle Friend, Include Youth, Institute for conflict Resolution, Northern Ireland Council for Ethnic Minorities, North West Belfast Health and Social Services Trust, Out and About group, Queer Space, Simon Community, Western Health and Social Services Board, Youth Action, Youthnet. Many thanks also to the individuals who took part in the focus groups.
- 2 Three focus groups took place: One in Derry which was attended by six young LGB people aged 16 to 24; one in Belfast area with six young LB women aged 17 to 27; one in Belfast with twelve young LGB people aged 16 to 24.

- 3 The focus group with health service providers was composed of six women working in Belfast/greater Belfast area.
- 4 Definitions available on the website *Schools Out! National* at http://www.schools-out.org.uk/san_definitions.html
- 5 For instance, GLYNI (Gay and Lesbian Youth Northern Ireland), an organisation set up to support young LGB people and offer them a safe meeting space, has defined its remit for young people in the bracket of 16 to 25 years old. The Youth Forum Northern Ireland has membership open to people between 16 and 25 years old.
- 6 There are fortunately a few exceptions (Health Promotion Department and Westcare Foyle Friend, 2001). A forthcoming research by Youthnet, YouthAction Northern Ireland, GLYNI, Foyle Friends, the Rainbow project & VSB is looking at issues around education of LGB (to be published).
- 7 The Office of the First Minister and Deputy First Minister published a grid surveying the research done by each department in different areas where Section 75 of the Northern Ireland Act, 1998 applies. It shows that the category “sexual orientation” has been greatly under-researched.
- 8 When asked how they found information on coming out and LGB issues, most participants in the focus groups mentioned the internet as a source of information. Some referred to phone-lines and other to LGB magazines.
- 9 According to research published in 1996, only 56% of secondary school and 54% of grammar schools have homosexuality covered as part of their sex education programmes. (Health Promotion Agency Northern Ireland, 1996).
- 10 “Traditionally used in the dentist’s office during dental surgery such as root canals, dental dams arrived in the height of the spread of STDs (Sexually Transmitted Diseases), predominantly AIDS. A dental dam is actually a small sheet of latex which acts as a barrier between the vagina or anus and the mouth. [...] These latex squares may provide some protection against the transmission of HIV and other sexually transmitted diseases.” Definition found on the following website <http://www.mama-shop.com/dentaldams/>.
- 11 Male sample: 232 and female sample: 130.
- 12 STDs stands for the term sexually transmitted diseases. This terminology is used throughout this report since it is the term used by the participants in the focus groups and also by the Committee on the Rights of the Child (and despite the fact

that there appears to be a consensus in Northern Ireland around the use of the terminology sexually transmitted infections (STI) instead of STDs).

- 13 Definition found on the website *Schools Out! National* at http://www.schools-out.org.uk/san_definitions.html
- 14 “Out and About” is a group working with young lesbians and bisexual women and is part of YouthAction Northern Ireland. “This programme has been running for two years with the Out and About Group meeting on a regular basis for eighteen months. Initially the group consisted of twelve young lesbians aged sixteen to twenty-five years from a range of locations in the Greater Belfast area. During this time the young women have had an opportunity to meet up in a safe environment, share experiences and identify the key issues that impact on the lives of young lesbians in Northern Ireland. They are currently in the process of developing ways to address these issues with a core group of eight members.” (YouthAction Northern Ireland, 2002).
- 15 Definition found on the website *Schools Out! National* at http://www.schools-out.org.uk/san_definitions.html.
- 18 Definition found on the website *Schools Out! National* at http://www.schools-out.org.uk/san_definitions.html.
- 17 A survey entitled “Combating Homophobic Hate Crime in Northern Ireland” is currently being undertaken by the Institute for Conflict Resolution. The survey will document further this issue.
- 18 “Much of people’s difficulties with the guidelines lie in the manner in which blanket exclusions of entire social groups are made without recourse to individual variation and behaviour. This, in turn, leads to concerns about the stigmatisation of those groups. THT believes that greater clarity about why the exclusions differ and why they are necessary would contribute to better public understanding of them, and decrease the unintended stigma currently caused by them.” (Trust policy on Blood Donation and Related Guidelines in the UK, agreed in November 2002.)
- 19 “Established in 1994, The Rainbow Project exists to address the physical, mental and emotional health of gay and bisexual men living in, working in or visiting Northern Ireland. Our main areas of work include: advocacy, information, support, research, counselling, prevention and education. We are Northern Ireland’s only gay and bisexual men’s health organisation and house the only gay male specific counselling and support service available in the north. We also disseminate free condoms, lubricant and safer sex information in gay and gay-friendly commercial

- and educational venues.” Information at <http://www.rainbow-project.com/>.
- 20 Under Section 75 of the Northern Ireland Act, public authorities have a duty to promote equality of opportunity “between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without.”
 - 21 In the case of *Gillick v West Norfolk and Wisbech Area Health Authority* (1985) 3 All ER 4092, the House of Lords stated that children under 16 of age could consent to medical treatment if they understand the pros and cons of that treatment. Although that case dealt with contraception services, the principle has been extended to all areas of medicine and dentistry. However, it does not apply to the refusal of medical treatment – parents can still over-rule children’s autonomy in that respect.
 - 22 In its clause dealing with non-discrimination (clause 4 chapter 4) the consultation document on the Bill of Rights extended the protection of the clauses to a combination of grounds, in Northern Ireland Human Rights Commission (2001).

REFERENCES

- Armesto, J. C. (2001) “Attributions and Emotional Reactions to the Identity Disclosure (“Coming Out”) of a Homosexual Child” *Family Process* available at http://www.findarticles.com/cf_0/m0AZV/2_40/76547775/p1/article.jhtml.
- Beaty, L. A. (1999) “Identity Development of Homosexual Youth and Parental and Familial Influences on The Coming Out Process” *Adolescence* available at http://www.findarticles.com/cf_0/m2248/135_34/60302525/p1/article.jhtml.
- Blumenfeld, W. J. (2001) “Adolescence, Sexual Orientation & Identity. An Overview” available at http://www.geocities.com/WestHollywood/Parade/9548/article_sexual_identity.html.
- Coalition on Sexual Orientation (CoSO) (2001) *A Guide to Involving and Consulting the Lesbian, Gay, Bisexual and Transgendered Community*, Belfast.
- CoSO (2001), *Submission to the Northern Ireland Bill of Rights Consultation*, Belfast.

Committee on Adolescence (1993) "Homosexuality and Adolescence" *American Academy of Pediatrics* available at <http://www.aap.org/policy/05072.html>.

Concluding Observations of the Committee of the Rights of the Child: United Kingdom of Great Britain and Northern Ireland 31st Session, 833rd meeting held on the 4th October 2002. CRC/C/15/Add.188.

Department of Education of Northern Ireland (1999) *A Youth Service for the New Millennium. Youth Service Policy Review*, Belfast.

Department of Health, Social Services and Public Safety (2001) *DHSSPS & HPSS Statutory Equality Obligations. Information Requirements: Data Availability, Quality and Deficits*, Stormont.

Eastern Health & Social Services Board (2001), *"Mum, Dad, I've Got Something to Tell You" A Guide to Parents who have Lesbian, Gay or Bisexual Children*, Belfast.

Family Planning Association & University of Ulster, (forthcoming) *Towards Better Sexual Health: A Survey of Sexual Attitudes and Lifestyle of Young People in Northern Ireland*, Belfast.

Feenan, D., Fitzpatrick, B., Maxwell, P., O'Hare, U., Ritchie, T. & Steele, C. (2001) *Enhancing the Rights of Lesbian, Gay and Bisexual People in Northern Ireland*, Northern Ireland Human Rights Commission, Belfast.

Frith, S. (1984) *The Sociology of Youth. Themes and Perspectives in Sociology* (Causeway Press Ltd: Lancashire).

Geraghty, T. (1999) *Getting it Right? The State of Children's Rights in Northern Ireland at the end of the 20th Century* Save the Children & Children Law Centre, Belfast.

GLYNI (2001), *Submission to the Children & Young Persons Working Group of the Northern Ireland Human Rights Commission*, Belfast.

Health Promotion Agency Northern Ireland (1996) *Sex Education in Northern Ireland. Views from Parents and Schools*, Belfast.

Health Promotion Department & Westcare Foyle Friend (2001) *Needs Assessment for the Lesbian, Gay, Bisexual & Transgendered Community in the North West of Ireland*, Derry.

Hedges, W. (1997) "Queer Theory Explained" available at <http://www.sou.edu/English/Hedges/Sodashop/RCenter/Theory/Explained/queer.htm>

The HIV Support Centre (2002) *Response to the Consultation on the Bill of Rights*, Belfast.

ILGA-Europe (2000) *Report Submitted to the Legal Affairs and Human Rights Committee* (Parliamentary Assembly of the Council of Europe), Brussels.

ILGA-Europe (2001) *Work Programme 2001/2002*, Rotterdam.

Lasala, M. C. (2000) *“Lesbians, Gay Men, and Their Parents: Family Therapy for the Coming-Out Crisis”* Family Process Rutgers available at http://www.findarticles.com/cf_0/m0AZV/1_39/61522927/print.jhtml

Nadri, P. M., Sanders, D. & Marmor, J. (eds.) (1994) *Growing Up Before Stonewall. Life Stories of Some Gay Men* (Routledge: London).

Noell, J. W. (2001) *“Relation of Sexual Orientation to Substance Use, Suicidal Ideation, Suicidal Attempts, and other Factors in a Population of Homeless Adolescents”* Journal of Adolescent Health.

Quiery, M. (2002) *A Mighty Silence. A Report on the Needs of Lesbians and Bisexual Women in Northern Ireland*, LASI, Belfast.

Rivers, I. (1996) *“Young, gay and Bullied”* Young People Now.

Seidman, S. (ed.) (1996) *Queer Theory/Sociology* (Blackwell Publishers: Oxford).

Simon Community (2000) *Opening the Door to Health. Access to Primary Healthcare Services for Single Homeless People in Northern Ireland*, Belfast.

Weeks, J. (1995) *“The Construction of Homosexuality”* in Widdicombe, S. & Wooffitt, R. *The Language of Youth Subculture. Social Identity in Action* (Harvester: Hertfordshire).

World Health Organisation (1997) *Young People and Sexually Transmitted Diseases. Fact Sheet No 186*, Geneva available at <http://www.who.int/inf-fs/en/fact186.html>.

YouthAction Northern Ireland (2002), *Out and About: Supporting Young Lesbians. A Model of Effective Practice*, Belfast.

Youth Council Northern Ireland (2001) *Seen and Heard? Consulting and involving young people within the public sector*, Belfast.

Youth Council Northern Ireland, (2002) *Barometer Update*, Belfast.

Youthnet, YouthAction Northern Ireland, GLYNI, Foyle Friends, the Rainbow project & VSB on the *Needs of Young People Who Identify as Lesbian, Gay, Bisexual or Transgender*, questionnaires available at <http://www.cara-friend.org.uk/glyni/survey1.html>

Zappone, K. E. (2001) *Charting the Equality Agenda. A Coherent Framework for Equality Strategies in Ireland North and South*, The Equality Authority & Equality Commission.

7 YOUNG ETHNIC MINORITY MEN IN BRITAIN

Colin Hann

7.1 INTRODUCTION

The focus of this part of the joint project is young ethnic minority men. The overall project is aimed at exploring the reality of the diverse make-up of people's identities as a way towards informing more effective equality and human rights strategies. A core consideration is to ensure that the stakeholder groups that are the primary concern of the equality agencies can have an input into what these organisations do, and how they plan their work. As Zappone writes, the overall project is concerned with "exploring how an understanding of inclusive equality can assist the development of strategies reflecting a comprehensive and integrated equality agenda" (Zappone, 2001).

One element of this part of the project has been carrying out a review of relevant literature. This literature is extensive, and given that this research project is small scale and exploratory in nature, we make only brief summary reference to this material.

The main part of the project was concerned with obtaining original information. This included carrying out interviews and discussion groups with:

- A number of practitioners, experts and academics in the field;
- Young Black men in Tottenham, London, associated with the Break Free project;
- Young Muslim male refugees in Glasgow associated with the Positive Action in Housing project.

Because of space limitations however, we have not been able to include the detail of the latter study in this chapter but make some reference to it in our observations and conclusions. The full study is available from the Commission for Racial Equality (CRE).

Unlike other studies in the project, we did not include health as a main focus of the study. In large part, this was as a result of young ethnic men not seeing health as a major factor in their lives. Hence we concentrated on exploring the broader themes of the study. Primarily, these were concerned with employment, education, housing, identity and other various individual perspectives.

7.2 BACKGROUND

The overall project is concerned with exploring the development of equality and diversity strategies that take account of the views and perspectives of the relevant groups or "audiences" themselves. Here, taking account of the legal context, a useful approach is highlighted by the concept of 'intersectionality': "intersectional oppression arises out of the combination of various oppressions which, together, produce something unique and distinct from any one form of discrimination standing alone" (Eaton, 1994).

Taking this approach means that there is an acknowledgement that this is a complex area and that people experience discrimination (or disadvantage) in various ways. Some may be unique, but all need to take account of social and historical factors. "It places

the focus on society's response to the individual as a result of the confluence of grounds and does not require the person to slot themselves into rigid compartments or categories. It addresses the fact that discrimination has evolved and tends no longer to be overt, but rather more subtle, multi-layered, systematic, environmental and institutionalised" (Ontario Human Rights Commission, 2001).

This approach poses a central concern of the project in terms of what are the identities of the groups being addressed? The "who am I?"; "what sort of person am I?"; "who do I belong to?" questions. What type of conclusions for example can be made about such groups as, young African-Caribbeans, Asians, Muslims, white men etc, and in what circumstances?

This is a complex area and there are no simple descriptions that can be ascribed to these particular groups, nor any "homogeneous" groups that can be conveniently labelled. Communities are: "not locked into unchanging traditions, but interact at every level with mainstream social life, constantly adapting and diversifying their inherited beliefs and values" (The Parekh Report, 2000).

As Modood and Berthoud write: "groups are constantly changing, re-writing themselves through mixing their traditions of origin with elements of the majority culture. The process of mixing and hybridisation will increasingly be the norm where rapid change and globalisation have made all identities potentially unstable" (1997). Hall adds that cultural identity is also concerned with constant change and with "becoming" as well as "being". "Cultural identities come from somewhere, have histories. But like everything which is historical they undergo constant transformation. Far from being eternally fixed in some essentialised past, they are subject to the continuous play of history, culture and power" (Hall, 1992).

Therefore in talking about disadvantages experienced by particular groups, there is a need to understand the complexity that lies behind various categories or identities. How do you talk about young ethnic minority men for example without resorting to stereotypes, and "criminalising" particular groups? For example, to look at drugs, or guns, it is important to recognise that this is a shared problem among many different groups. Where are the similarities, where are the differences? What makes a Black, or white, or Asian crime different? Are there things specific to the group, or not?

There has also been uneasy tension and discussion and debate on racism and institutional discrimination, at the general level, but when we look at particular towns and local level issues, such general discrimination does not necessarily elucidate what is really going on. A good example is the recent Bradford, Burnley and Oldham disturbances, where the "general" explanations could not necessarily explain the particular. The experiences of Pakistanis and Bangladeshis for example, may be shaped by racial discrimination, policing, employment and education, etc., but when looking at individual events in localities, the situation can be more complex. Hence it is not

sufficient to develop policies at general levels to tackle racism and discrimination. There is also a need to move down and develop local initiatives in local areas to address particular challenges and dilemmas. In our case studies for example and in the other studies of the overall project, while general descriptions of discrimination and disadvantage may be relevant, very different problems and issues are presented as well as potential solutions.

7.3 YOUNG ETHNIC MINORITY MEN: BRIEF BACKGROUND DATA

A summary of some relevant facts and figures is provided at Appendix 1 on young ethnic minority men. Within this diverse group it is also emphasised that any trends will be shaped by such areas as gender and class.

Overall background indicators show that ethnic minorities generally have a significant younger profile, with for example 48% of the ethnic minority population being under 24 compared with 31% of whites; and the median age of ethnic minorities is on average 11 years less than white people. In terms of education, outcomes are different between groups. Members of most ethnic minority groups tend to stay on at school longer than white teenagers, but African-Caribbeans have lower staying on rates than whites. There are different figures between groups in terms of qualifications, with Africans having the best qualifications and Pakistanis and Bangladeshis being the least qualified. African-Caribbeans have fewer degrees than others, and are also behind whites in the number of A-Levels achieved. Young African-Caribbeans continue to be more likely to be excluded from schools than any other group.

In terms of employment, there are significant differences with unemployment rates for young Black people being 35% compared to 13% of young white men. There are differences between ethnic minority groups with Bangladeshis and Pakistanis more likely to be unemployed than others, but with young Indian men having similar patterns to those of white men. Among those with a job, young Indian men are at least as well represented in managerial positions and the professions as young white men. African-Caribbeans are under-represented in these professions, and Pakistani and Bangladeshi young men are over-represented in semi-skilled and unskilled work.

One area of concern that is also raised in this report is that the relatively poor performance of some young Black men in the labour market may generate negative stereotypes of some young Black men in general: “the real danger in these negative stereotypes lies in young people’s aspirations being suppressed as a result of others low expectations of their potential. If transferred to peers and between generations, this could lead to cycles of discouragement and further social exclusion” (Saggar et al, 2003).

There is no simple source of data in terms of young ethnic minority men and health, and in any event it is not seen as a particularly significant issue for young ethnic minority

men, primarily because of the young age profile. However, there is over-representation of African-Caribbeans admitted as patients with illnesses associated with mental health. A recent article summarised: “some claim that African-Caribbean people have a biological pre-disposition to schizophrenia and other psychoses. Others, that the high number of African-Caribbean people diagnosed with schizophrenia is the result of misdiagnosis. Still others argue that the instance of psychoses is directly related to social environment: unemployment, deprivation and racism all being contributing factors” (Pinto, 2002).

Ethnic minority men are more likely to live in disproportionately poorer housing, although there are differences between groups, with Bangladeshis and Pakistanis significantly more likely to live in the most deprived wards. In terms of criminal justice, young African-Caribbeans are more likely to be stopped and searched by the Police than other groups, and this group also continue to figure disproportionately in the prison population.

Overall, although there are variations between the different groupings, a recent report by Saggar et al, notes that in respect of many ethnic minority groups: “evidence suggests that racial discrimination and harassment persist today, despite the enactment of existing anti-discrimination legislation measures, although these have tended to become more covert thus less easy to tackle” (Saggar et al, 2003).

7.4 BREAK FREE PROJECT: TOTTENHAM

For this part of the study we conducted a number of interviews with Black (African-Caribbean) young men attending the Break Free Project in Tottenham. (In our project, including the 2 studies, we interviewed 18 young people, held 2 discussion groups and interviewed 12 practitioners/academics). Break Free is a project run by the young people’s charity RPS Rainer. The project aims to help young people to meet their potential, and targets young people who have been excluded from school, have not got any qualifications, have been in trouble with the police or been in prison etc.

We interviewed a range of young people, as well as project staff. All those we interviewed were Black and between the ages of 16 and 24. All lived at “home” or with relatives. All had left school as early as possible with only basic minimum qualifications.

7.4.1 The “Early Years”

As we have seen, although problems are varied, African-Caribbeans tend not to do as well in the education system as many other groups. Importantly they also continue to be significantly more likely to be excluded than other groups.

In terms of our group, although their schooling was varied they all had had less than successful experiences. The majority had been in continuing trouble; some had been expelled, and moved from school to school. Others had had periods of exclusion.

We explored a number of their perceptions of school. Most of the interviewees said that when at school they were not particularly aware of any race dimension. However, they said that in retrospect things looked slightly different: *'looking back there was something; most of the exclusions for example were for Black pupils'*. There was a feeling expressed that for similar offences, Black pupils would be excluded, while white pupils would be given 'the benefit of the doubt'. One interviewee said: *'Black kids were dealt with straight away, others were given a chance.'*

Another said: *'I think I was labelled at school, a short time after I started. Anything that went wrong I would be blamed for. I was put in a category and the teachers would not change their minds.'*

When asked about the groups they mixed with at school, all said that, looking back, whilst white, Black and Asian kids, etc. may stay together for parts of the day, there was also a lot of intermingling. One person said: *'In some ways there was separation, in other ways we were all part of a group.'* Another said that the reason that Black kids may have tended to be with each other at times was: *'it was a difficult environment, and perhaps it was our way of handling it, so we stuck together. Maybe it was our cultural background that brought us together.'*

While looking back and saying that they thought racism was a factor in their school lives, at the same time the interviewees did not emphasise this factor. They acknowledged for example that most of the teachers 'were ok' although they viewed a minority 'as racist' and 'we all knew who they were'. One interviewee summed the views of most: *'The majority treated everyone equally, but Black pupils were sometimes treated differently by some. Discipline seemed to be enforced by them more for Black students than for white students. They seemed to see white students as having more potential to achieve compared to us.'*

In terms of exclusion, whilst noting that race seemed to be an important factor many of the interviewees also said that pupils were often excluded simply because their behaviour was "bad and unacceptable".

One overwhelming perspective that arose in our discussions on schooling was a feeling of regret. *'If I knew then what I know now, it would be very different. I would (and could) have passed all the things I needed to.'* Another said: *'I have learnt from my mistakes.'* Another: *'My mum was right, I should have worked and not messed around all the time.'*

7.4.2 After School

All interviewees had left school as soon as they could and with minimal educational qualifications. As those working on the project said, this was a key factor: *'those who had achieved qualifications, we never see them.'*

After leaving school, interviewees had varied between going to college, having jobs, having periods of unemployment, and getting "into trouble". They said that they had left school because of their poor exam results, but also because they did not see staying on at school as a positive or viable option.

Many had gone on to college for various phases and with varying degrees of success. Many had started courses and then left them; some had completed part of a course and then left and planned to return. *'I left college, I couldn't hack it, I needed money, I wanted money.'*

The courses attended were primarily related to IT and computer training and also the "creative" industries of media and music. However several had gone or wanted to go to colleges outside the area: *'There is a feeling round here that people do not go to college to learn'*. They said that they knew too many people and that it was too much of a distraction to go to college with people they knew. *'I want to go somewhere else where I can study seriously.'*

In terms of jobs, all the interviewees had had a variety of jobs but usually moving from one to another. Most said that they had not had a great problem getting jobs although these were mostly low-paid. They had subsequently left them usually because someone had upset them, or it was simply too repetitive and boring.

Some had been sacked from their jobs and some of the interviewees alleged that this was because they were Black. In terms of discrimination in jobs, all the interviewees were aware of potential barriers because they were Black: *'Discrimination against Blacks happens all the time. I know I am treated differently sometimes, because I am Black. But I am used to dealing with it, if I get rejected, I don't get hung up, if it happens it happens.'*

Another interviewee said: *'I have had plenty of jobs, and I am used to interviews and I had bought myself a new suit for this one. I looked good. But when I walked into the room I knew that as soon as they looked at me that I had no chance because I was Black.'*

However the interviewees did not over-emphasise the factor of discrimination although they knew it existed. Many of them were aware of discrimination but did not necessarily have personal experience of it. Often they saw it as a one off case. One interviewee said: *'I know people discriminate, but I have never met it myself really, and have never really thought about it.'* However we noted that none of the interviewees were aware of their rights under equality legislation.

All the interviewees had had problems about getting past the CV application stage, as they had little experience and minimal qualifications. However the majority were confident, that if they got through to the interview stage they would get a job. A typical comment was *'I'm good at interviews, if I'm given the chance I can sell myself.'*

One issue was criminal convictions. Those who had them found it a major hindrance to obtaining jobs. They did sometimes succeed in getting jobs but these were usually poorly paid or on a temporary basis. Some had lied about their previous convictions and had subsequently been sacked when they were found out. These convictions were for relatively minor offences, and the interviewees felt strongly that this should not necessarily blight them for life, and stop them having a chance of ever getting a decent job.

7.4.3 Living

Most of the interviewees lived in Tottenham, and had done so for most of their lives. They lived predominantly in social housing usually with their direct families or relatives. Racial harassment was not seen by them to be an issue in the area; although those who had lived outside Tottenham for any time said that they had experienced such harassment, usually abusive name calling by teenagers.

In terms of feeling safe in their immediate neighbourhoods, they generally said that they "felt safe" as they knew the streets and were known. However at the same time their view was that Tottenham was getting less and less safe: *'There are no race attacks, but it is not safe. It is safe for me because I know people and I am OK. For others it is not safe. There are attacks, shootings and robbing.'*

Interviewees talked of increasing crime and attacks and that the area was getting worse. They said there are more guns, they are everywhere: *'there is lots of trouble on the street, lots of guns, but I can look after myself.'* The existence of guns was seen as "a fact of life" in Tottenham. *'There are lots more guns – I think it is the American influence. People don't want to be left out of it'* and *'I have seen guns I thought no-one could get hold of. If you know what you are doing you can get guns.'*

Interviewees saw guns and drugs as the reason Tottenham was now more dangerous and not *'a safe place to live in any more.'* Whilst loyal to Tottenham, as this was an area where things *'were happening'* they generally saw their future as not living there. *'All you've got in Tottenham and London is going to prison. There is nothing productive, nothing to do.'*

Some had lived parts of their lives involved in or on the periphery of crime, and they knew people who lived their lives by crime. While generally not part of this, as they had moved on, several of the interviewees were cynical and resigned to such lifestyles being part of the reality of life for them in a place like Tottenham. They saw crime as an inevitable part of some people's lives, their destiny. As one interviewee said *'what do*

they have? Nothing. Their families have nothing; they don't get on at school. It's their way of arriving (getting into crime), getting acceptance. They don't want to get a job, and anyway they can't because they've got a criminal record.'

Most of the interviewees had had direct experience of the police, and all had been stopped and searched. They felt however that this was probably happening less frequently than it used to. Some of their experience at the hands of the police had been heavy-handed and abusive. However they had also had experience of police being reasonably professional and efficient. To all of them, stop and search was seen as a fact of life. They did not like it, felt that it was unfair and happened to them because they were Black, but there was an overwhelming feeling of resignation on the issue.

How did the interviewees describe themselves, and who did they spend their time with? While aware of their Black identity, and aware of what it could also mean in terms of possible discrimination and racism, the interviewees in the main did not see it as a defining factor in their lives. In terms of other aspects of their identity, age and male, they did not isolate these factors as being separate parts of themselves – they saw themselves as being 'one'. Most said that while many of their friends were Black, they also had friends from other ethnic groups. All of them mixed with white people, and other ethnic groups. *'I have had white friends, but most now happen to be Black....this is not because of discrimination or culture, it is just what happens – I still have lots of white friends.'* Another said *'I don't care who it is ... I am multi-cultural ... I don't keep a note of what colour my friends are, I don't think about it at all.'* And another said *'White people tend to maintain their own culture, Black people do the same, but we also mix together. There are racists I meet, but most people are not'*.

The schools, the "street" music were factors as they saw it in their *'open approach to race.'* They felt it reflected London, in that Tottenham was just one part of such a diverse area. *'In London people have to get along with each other, and mostly they do.'*

In terms of future prospects, most of the young people had on the face of it "failed" in the past, especially in terms of education. Some had criminal records; some had spent time in institutions. However despite this, the majority were relatively optimistic about the future. They had goals and aspirations (despite past failures), mostly because they had made the decision to do something. Many were aiming to finish college, go back to college, obtain qualifications and some intended to go to university. Others were working to get a job or working to get a better job. They saw themselves primarily as working in the future, earning a living and achieving.

There was in fact a level of determination and focus in all of them, even though some of this might have been bravado. In short they were self-motivated, or had re-discovered self-motivation. Part of this was in their decision to involve themselves in a project such as Break Free. In our interviews we could see the positive impact such a project can have. All the young people attending Break Free were positive about it. A typical

comment was *'they give me support, help me make sense of things and get where I want to be – although they sometimes give me a hard time.'*

7.4.4 View of the “Practitioners”

In addition to the young men at the project the views of those working there and also other practitioners were important, and added to the picture presented. A common view was that many of the young men did not “understand the system”, perhaps a reflection of their youth. They had, in a way, had most things done for them for most of their lives and suddenly they'd had to deal with life especially when they left school. They did not know what to do: “where do I fit into society?”. Not knowing led to offending. One worker said that many of them *'seem not to love themselves anymore – they are a bit lost.'* And: *'things seem to so often go wrong when leaving school....this is a situation where their parents are not in a position to help. In addition there is often the problem of drug abuse.'*

One practitioner, again emphasising the role of education, said that because of an insufficient education, this led to under-achievement as well as exclusion from society. In their view there is also a lack of strong parental control (and many had come into conflict with their families), and a weak community infrastructure unable “to support” this group. They added that there are problems for young Black men in terms of how they presented themselves for work in a world that sees them in terms of their aggressive and “criminal behaviour”. *'Respect in this world is very different to the notion of respect in mainstream society.'*

In leaving school without qualifications peer pressure was also seen to be very important. Often it was seen that behaviour was defined by those close to them. There was a view (and reflected in the interviews with the group themselves), that if they really wanted to succeed, then they needed to move away from the people that they had grown up with, in order to break patterns of behaviour and in order to succeed.

Housing was also seen to as a major issue, although not particularly by the young people themselves. Many of those attending the project did not have a permanent home or came from unhappy ones. One issue, was that often young people at the project were simply very hungry and sometimes had eaten very little or nothing for several days. This is something the project had had to address.

7.5 OBSERVATIONS AND CONCLUSIONS

In terms of culture, various observations were made by those associated with the project. It was felt that many of the young people were not really aware of their “own” culture or had a strong feeling of identity. It was no longer based on a West Indian or African culture, and is related to a Black British culture, that has a mix of influences. There was a view that Black and white young people often see themselves in a similar

way (in an area like Tottenham): *'They talk the same, have the same street talk, and music seems to be a major influence that brings people together.'*

While this part of the project was concerned with three facets of identity, age, ethnicity and gender, we found however that the young people we met with did not particularly identify themselves with any of these, and indeed reacted against being described in any particular way at all. Their Black identity was important to them, but it was not something they thought much about, and did not view it as necessarily having a major impact on their lives. Externally, however, there are negative stereotypes that are attached to this composite group, relating, for example, to exclusions, crime and image that our group were aware of, and felt labelled with at times. At the same time they were an active part of the 'stereotype', as referred to both by themselves, and particularly practitioners who worked with them, in that they had been in trouble at school, or with the Police.

In terms of discrimination, although aware of it as an issue in relation to race, they had not in their view had many personal experiences of it. In fact, apart from the Police, they did not see any of the major institutions as presenting any particular barriers to them, because of any part of their identity, except looking back, aspects of the education system. One view, as we have seen, is the feeling of regret that the young people had in not doing more at school and "getting into trouble", and hence missing out on opportunities.

As we noted, in relation to potential discrimination, the young people we interviewed were not aware of equality legislation and knew nothing about the work of the equality agencies. This has implications for the CRE in terms of its information work and campaigns.

However, in our discussions with practitioners and others, while recognising discrimination as an issue for ethnic minority men, they felt that matters were more complex than this. Background influences and culture were as important. Addressing solutions and developing relevant strategies for addressing some of "the problems" associated with young men were seen to be highly complex.

For example, self-esteem was seen to be an important factor with low self-esteem seen to provide lack of knowledge about self. As one of the interviewees outlined, one of the following responses may be initiated: *'First, you become withdrawn and in order not to say the wrong thing you do not engage at all. Second, you react but say the wrong thing: this group is bright but has a false sense of confidence.'*

A related issue that was raised was the need to be able to establish who the successful Black males in society are (as well as other groups), and positive role models who can influence and inform the experience of such impressionable young people. Many of the practitioners argued that Black young men need mentors in their lives and in their

localities. As one said to us: *'If they see the successful ones then they can aspire to success, instead of life on the streets and the sub-culture of crime and violence.'* The use of mentoring initiative has implications for the types of strategies that may be relevant in this area.

In terms of how the groups we interviewed described themselves, their "identity", however it is made up, was not seen as a paramount issue, and indeed both groups that formed part of our overall study did not like addressing any issues and problems in these terms. In fact some argued that dwelling on their ethnicity or religion would *'reinforce the stereotypes about these groups'* which they themselves personally did not feel an association with. The young people we interviewed wanted to describe themselves and their experiences without labelling.

For the young Black men, common themes emerged which reflect in part the overall data on this group. They tended to fail in the education system under the age of 16, and although they had little trouble in obtaining jobs, they tended inevitably, because of lack of qualifications and experience, to be of low status and pay. Obtaining qualifications, be it belatedly, was seen as a way out and of moving on, or the alternative of exploring "creative" areas such as music, were also seen as an escape to something better.

Many of the young people had been in serious trouble with the police but at the same time did not like the fact that the area of Tottenham, as they perceived it, had become increasingly dangerous in terms of crime, and in the use of guns. Both groups we met, were relatively young, and for the Tottenham group this was an important external factor. They were full of a considerable amount of bravado, but at the same time they were quite naïve and did not really know how the "system" worked, or necessarily how to take advantage of it.

Discrimination, in the meaning of the law, as such was not seen to be a major factor, both from the perspective of the interviewees and of the practitioners and academics, and more intangible factors to do with poverty, family, youth culture, and background were more important. References were made by the practitioners, to the need of a range of various interventions and possible solutions. These were primarily concerned with building up the confidence of the young people themselves including development of such areas as mentoring, positive role models, and dealing with issues of low self-esteem, etc.

These type of interventions provide considerable challenges, and it may well be the case that these issues are best addressed by specialist local agencies such as Break Free.

In terms of the two groups that were the subject of our study, despite differences, there are also two important overall background themes, that are relevant to further exploration in not only this area but for the project as a whole.

7.5.1 'Labelling' and stereotypes

First, one part of the concept of identity is concerned with “Britishness” and belonging, and much has been written about this in recent years. In particular, what it is, and what it is not, to be British. Certainly the media have paid a considerable amount of attention to this issue in recent times. The media is an important part of the story about how perceptions of identity and people are developed, and how we see things and how we see ourselves. This can impact on our influences and decision making processes at both the conscious and subconscious level. Important here also is the way such areas as race, criminality, asylum seekers, refugees, culture, immigration, and Islam for example are represented.

We see how images, and stereotypes, can be played out over time, relating to “immigrants” and newcomers and “those who are different”. Such communities can be seen as alien. As Gilroy writes: “the enemy within, the unarmed invasion, alien encampments, alien territory and their commonwealth occupation have all been used to describe the Black presence” ... “Black people are seen as outside British culture”.

There is a media pre-occupation and even obsession with stereotyping various groups. The two groups that we looked at bear the brunt of this. Young Black men are tainted as a group with exclusions, attacks, muggings, drugs and now guns. Asylum seekers (the subject of our second study and not included here) are tainted with cheating, scrounging and now terrorism. However, in recent years the stereotypes attached to young Black men are also extending to young Asians. With the recent disturbances in Bradford and Oldham and other events changing the view of this group: “where the former were wracked with tales of cult, generation gap, lack of parental control, alienation and despair, British Asian communities were held to be, by contrast, holistic and coherent, alien and incomprehensible perhaps, but peaceful, law-abiding, successful and the odd scare about immigration aside, largely unproblematic.”

Overall images are changing, at least in the media’s eyes, with a new emphasis on Muslims. Bradford, the Gulf War, 9/11, the Taliban, and the associations between these areas, has resulted in Black and white divisions being replaced by British and Muslims, with Muslims placed as “the new social and cultural pariahs” (Alexander, 2000). At the time of writing, asylum seekers were the new “enemy” with hysterical campaigns being run by the media, notably by The Mail, The Sun and The Express.

Labelling, stereotyping, therefore is a problem for all young people and needs to be taken account of in any research in this area. A useful reflection of this and referred to by Claire Alexander (2000), is the example of the poster called “common assumptions about the Asian community.” The poster is a cartoon depicting two Asian men, one with a goatee beard and Muslim headgear telling the other: “I suppose that you being Gujarati, and me being Bangladeshi, and being born 4,500 miles apart, you can forgive them for thinking that we are the same.”

7.5.2 Similarities and differences

Second, in terms of concepts of identity and describing people, the category of Black and ethnic minorities are often used very loosely as the issues affecting various groups are different at different times. Currently the issues facing African-Caribbean young men are still the traditional ones such as stop-and-search. Issues relating to school experience, and the complexity of these is increasingly being understood. As we have seen there is the example of underachievement at school, but the reasons for this are not simple. Questions are now beginning to be asked about what this underachievement means and importantly how it can best be addressed.

Just as relevant is that the experience of young Black men is not necessarily fundamentally different from that of young white men or young Asians. Young Black men face problems of living in urban environments where pressure and stress to survive in a background of neighbourhoods where there is crime, is the same for all groups in such areas. Again, as we have seen, in such environments it also becomes difficult to disengage from peer pressure.

Hence finding solutions is inevitably a mixture of developing the 'general' – law enforcement, promotional and educational initiatives and campaigns and also looking at the particular and the 'local' situation. The practitioners and academics we met with also argued for the need for long term research studies that will enable more understanding of what is happening amongst various groups. This also related to the work of agencies such as the Equality agencies. As one practitioner argued: *"we need to find more ways of determining what is actually happening in our communities. Our policy and practice needs to be informed by empirical research and consultation with communities – we need to make real connections with grass root communities so that the work of agencies such as the CRE reflects this."*

REFERENCES

- Alexander, Claire (2000). *The Asian Gang: Ethnicity, Identity and Masculinity*. Oxford: Berg.
- Pinto, S. 'Padded Walls' (2002) in *Connections*, Autumn, London: Commission for Racial Equality
- Eaton, M. (1994). *Patently Confused, Complex Inequality and Canada v. Mossop* (1994) 1 Rev.Cons.Stud.203 at 229.
- Modood T. and R. Berthoud eds. (1997). *Ethnic Minorities in Britain: Diversity and Disadvantage*, London: Policy Studies Institute.

Ontario Human Rights Commission (2003). *An Intersectional Approach to Discrimination: Discussion Paper*.

The Parekh Report (2000). *The Future of Multi-Ethnic Britain*. London: Profile Books.

Saggar et al (2003). *Ethnic Minorities and the Labour Market*. London: Cabinet Office.

Zappone, K. (2001) *Charting the Equality Agenda*. Equality Commission for Northern Ireland/The Equality Authority.

APPENDIX 1: BACKGROUND DATA ON ETHNIC MINORITY MEN

It should be noted that the main sources of data continue to be the 1991 Census (data from the 2001 Census will be available soon), the Labour Force Survey, along with a number of dedicated studies.

General

- 48% of the ethnic minority population are under 24 years of age compared with 31% of whites.
- The median age of ethnic minority groups are on average 11 years less than white people.
- Ethnic minorities are concentrated in urban areas: for example 20.2% of Greater London's population and 14.6% of the West Midlands population are from ethnic minority groups.
- In rural areas ethnic minority groups constitute 0.7% of the population.

Employment

- One in eight white men in their 20s were unemployed (figures for Indians were very similar). Proportions for African men were one in three with Caribbeans/Pakistanis and Bangladeshis nearly as high.
- More than 40% of 16-17 year olds from minority groups were unemployed compared to 18% of whites.
- Among those with a job, young Indians were at least as well represented in

managerial posts/professions and other non-manual jobs as young white men. Caribbeans were under-represented in these occupations. Pakistanis and Bangladeshis were over-represented in semi-skilled and unskilled work.

- Despite high levels of self-employment among minority groups, self-employment results only in about 7% of all small businesses being in ethnic minority hands.

Earning Power

- Young Indians and white men are broadly in the same position. Young Caribbeans and Africans, have an earning power less than two thirds of whites. Young Pakistanis and Bangladeshis have not much more than half the earning power of whites and Indians.

Education

- Education outcomes vary greatly between groups. Members of all minority groups are more likely to stay at school after minimum leaving age than white teenagers. 81% of 16-19 year olds from ethnic minority backgrounds received education and training compared to 67% of young white people. However there are differences between staying on rates, with Caribbeans staying on rates being slightly lower than whites.
- There are different figures in terms of qualifications. Overall, Africans are the best qualified ethnic minority group in the UK, and Pakistanis and Bangladeshis are the least qualified. It was found that Caribbeans are on a par with whites, but there are some variations. For example, Caribbeans have fewer degrees than any other group. Caribbean men are also behind whites in the number of A-Levels, and the trend suggests that they may be falling behind.
- Data over recent years has shown that young African-Caribbean men are more likely to be excluded from secondary schools than any other group.
- Even controlling for such factors as age, social class and entry qualifications, ethnic minority students are less likely than whites to obtain admission to traditional universities.

Housing

- Ethnic minorities tend to live in disproportionately poorer housing. Ethnic minorities are more likely to live in deprived wards irrespective of tenure. This is especially true for Pakistanis and Bangladeshis, and to a lesser extent for Black Caribbean groups.

- Ethnic minority households are more likely to be overcrowded. A survey of English housing has shown over 25% of Bangladeshi and Pakistani households were overcrowded, compared with 8% of Indian households, 7% of African-Caribbean households and 1% of white households.

Health

- There is no simple source of data in terms of young ethnic minority men and health. Overall this is not a significant issue for young ethnic minority men. However there is over-representation of African-Caribbeans admitted as patients with illnesses associated with mental health.

Young Offenders

- Information from the British Crime Survey suggests that nearly half of all violent crimes are committed by 16-25 year old men. A Home Office study of young people found that Black and white 14-25 year olds were equally likely to have committed an offence with much lower figures for South Asian young people.
- Young male offenders under 21 years made up 18% of the prison population in England and Wales. Black Caribbean young male offenders were disproportionately represented with 9% of the total being from this group.

Policing

- Young people from ethnic minority groups are more likely to be stopped and questioned by the Police than white young people. Figures for 1996 suggest that 59% of the people stopped and questioned by the Police were from ethnic minorities.

8 CONCLUSION: THE CHALLENGE OF DIVERSITY

Katherine Zappone

8.1 INTRODUCTION

This joint research project aims to increase knowledge about diversity in people's identity. This is a much-needed endeavor as equality and human rights bodies face the enormous challenge of promoting rights and equality for everyone within their respective jurisdictions. The social and cultural make-up of Ireland, Northern Ireland and Great Britain is not homogeneous and is indeed becoming more and more diverse.

It is no longer sufficient to develop policies and strategies that promote greater access to and benefit from society's resources for *homogeneous* groupings of 'disabled people', 'women', 'young people' or 'Black and minority ethnic people'. It is not simply about encouraging recognition and participation of heretofore excluded social groups. To accommodate the diversity of *everyone* goes deeper than that, requiring a more complex understanding of people's identities. A one-dimensional analysis of who people are and what they desire to live a life of freedom and responsibility is no longer adequate. Acknowledgement of differences between social groups must be complemented with recognition of diversity within social groups.¹

The preceding chapters bear this out. Each study explored the experiences of a group of people who share two characteristics or social categories that contribute to their 'multiple identities'.² The research listened to these people reflect on who they are and what their experiences have been, especially with respect to accessing basic services in their society. This was complemented with statistical and other research data about people with these characteristics. In every case this exploration reveals a more complex picture of how these individuals struggle for equality and recognition of their human rights and outlines how they experience considerable discrimination and exclusion because there is little recognition of their multiple characteristics. The chapters in this report highlight the immense personal suffering of individuals who do not fit the prescribed norms of a society on a number of fronts. They point toward the need for deeper attitudinal and institutional change if people are to encounter more fairness, equality and justice in their day-to-day lives.

8.2 MAKING DIVERSITY VISIBLE

8.2.1 Multiple Identities – Distinctive Characteristics

When inviting people to define themselves, it became quickly apparent in all the studies that people offer explanations that encompass **multiple** attributes. Even though the research focused on two categories common to a group of individuals, such as ethnicity and gender, research participants talked about additional factors that influence their experience of the world. The Equal Opportunities Commission (EOC) study on Black and minority ethnic women points out that,

"The women have multiple experiences in terms of age, sexuality, disability, religious and cultural differences. For example, an older Asian widowed woman who has worked in the family business will have a very different identity and face different equality

issues compared to a younger professional Somali woman refugee doctor unable to secure employment. Each woman therefore has a different ‘story’ to tell” (27).

The Disability Rights Commission (DRC) study on lesbian, gay and bisexual disabled people refers to previous research that depicts this multiplicity in another way.

“Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race . . . everything finally piling into a single human body” (50).

There is a sense of movement in these words. They evoke the notion of **fluidity**, which is a term often used to describe the shifting and changing character of how people identify themselves. The Equality Authority (EA) study on minority ethnic people with disabilities discusses a sense of fluidity that emerges from the interviews.

“At any one time, a person may hold multiple identities, but choose to assert or express an identity that is most meaningful to them at that time or in a particular context. For example, one participant in the study expressed her ethnic identity through her participation in an African choir. This does not mean that ethnic identity is the totality of her identity. Her identity as a woman, a disabled person, a parent and a woman living in poverty were also important components of her identity” (15).

As described here, people’s expression of identity also can be **context-dependent**. They will claim different aspects of their identities in different circumstances and at different times. Sometimes this has to do with how safe they feel about who they are in a particular situation. Several studies pointed out that people are afraid to disclose an aspect of their identity because of anticipated consequences. The DRC study refers to a disabled woman’s fear of discriminatory treatment: *‘at the ordinary [women’s reproductive health] clinics they assume that I don’t have sex. I don’t tell them otherwise because they are known to be homophobic’* (55). The EA research records the concerns that can arise for a disabled Black person when searching for a job, *‘I don’t state in my CV that I have a disability. I know that would definitely scare them away from asking me to come for an interview’* (20).

These examples indicate the conflicts that are part of people’s lives when one or more aspects of their identities result in experiences of direct and indirect discrimination. A group interview from the Equality Commission for Northern Ireland (ECNI) study on disabled women describes these tensions well.

“As one participant said [...] *‘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 around womanhood are first.’* Another participant disagreed because 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 or fundamental’* (77).

These sentiments express a sense of **contradiction**. As pointed out in the EA study, the fact that people hold multiple identities “means that their social relations can be multi-faceted and imbued with contradictions. This has implications for identity. Certain social interactions can reinforce a positive sense of identity, while simultaneously, other social interactions can undermine a person’s sense of identity” (15).³ On the one hand, minority ethnic people with disabilities may feel valued as members of their ethnic community. On the other hand, they may experience marginalisation in the wider society on the basis of this same ethnicity.

8.2.2 ‘Otherness’ and Multiple Disrespect

The concept of ‘otherness’ refers to the fact that many people - by virtue of some aspect(s) of their identity - do not fit what a particular society has defined as a ‘normal’ human being. They are ‘other’ than ‘normal’ because of a physical impairment, a minority ethnic background or a minority sexual orientation. ‘Otherness’ can mean feeling as though one is on the outside, does not belong, is stereotyped or disrespected. These experiences are usually shaped by interactions with other people, especially those who fit the ‘norms’ of, for example, non-disablement, a majority ethnic background or a dominant sexual orientation. A feeling of ‘otherness’ can also be due to how systems are organised, for example, a system of health provision or education that some people do not have equivalent access to or benefit from.

The studies in this joint project present again and again the impact of ‘otherness’ on people’s lives. As one reads the varied accounts, the weighty disrespect for those with multiple identities becomes clearly visible.

The Northern Ireland Human Rights Commission (NIHRC) research records what the intersection of youth and sexual orientation in one’s identity can mean for some.

“Several participants referred to their experience of stigmatisation, name calling and bullying at school. *‘I came out when I was 14 and I’m always being labeled as the ‘lesbian’ at school.’* During the focus group with service providers one participant said: *‘On our boy’s playgrounds, they know that the worst thing that they can be called is gay. Five and six year olds are saying it without having any idea of what it means [...]’* One young woman reported *‘when I was 14 or 15, I got kicked and pushed everyday coming home from school.’* Another participant mentioned his experience of seven years of bullying. There was no support to deal with homophobic bullying; it was not even acknowledged that it was happening in the school” (98).

This leads to clear examples of **suppressed identity** precisely during a period of life that accents its formation. 'Youth' was a focus also of the Commission for Racial Equality (CRE) study on the ethnicity of young African-Caribbean men. Reflecting on his experiences at school one of the research participants said,

'Black pupils were sometimes treated differently by some. Discipline seemed to be enforced by them [the teachers] more for Black students than for white students. They seemed to see white students as having more potential to achieve compared to us' (118).

The ECNI research on disabled women uncovered the complex and often painful interplay of gender and disablement. A number of the women in the study 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'* (79). This provides an example of how hitting up against a stereotype with respect to one aspect of identity - in this case, impairment - can **negate** another aspect of **identity**, namely gender and motherhood. The ECNI research further reports: "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" (80).

The studies also reveal the **interlocking structures** of exclusion that can be faced by people with multiple identities. As pointed out in the EOC study, "patterns of ill health for Black and minority ethnic communities in Britain, related to social disadvantage such as poverty, housing, safety and living in insecure situations, are well established" (27). The findings of this research indicate however, that Black and minority ethnic women feel the weight of multiple disrespect through ill-health due to expectations of their gender role as well as through the risk of poverty because of ethnic background. The EOC study offers the following analysis of some of the women's stories.

"Pride in the home, as good homemakers is crucial to 'who they are' as wives, mothers, daughters. Therefore living in cramped, unhygienic unsuitable conditions over which they have no control means that an essential part of who they are as 'women' is negated - this results in constant stress. *'There are too much problems in my home - it's so dirty - I worry all the time about it - it affects my health I can't sleep - for real I can't sleep - I worry all the time'* (Turkish mother age 32, living in U.K. 3 years)." (28).

Gender role expectations intersect with societal treatment of Black and minority ethnic people such that some of the women in this study become ill. Similar to analyses offered in the studies of disabled people, people can become dis-abled because of the multiple ways in which social systems fail to recognise difference especially through stereotyping. Furthermore this failure can effect additional debilitation, as it is often these same people who experience the exclusionary consequences of poverty. The CRE research, for example, documents that often the young African-Caribbean men they

spoke with “were simply very hungry and sometimes had eaten very little or nothing for several days” (122).

Disrespect and mis-recognition is experienced also, as people look for a sense of community and affirmation in social groupings or political movements. Some participants in the DRC study, for example, talked about their sense of exclusion as lesbian, gay and bisexual disabled people *within the disability movement* because of its homophobia. One person said, *‘There are a lot of people I know in the disability movement who daren’t come out in their organisation’* (56). On the other hand, research participants felt that “there was a good deal of disablism within the gay and lesbian community. The ‘body beautiful’ culture and perceived focus on youth (was) cited by all participants as something that makes it difficult to feel comfortable with the lesbian, gay and bisexual community. This **invisibility** of people with ‘multiple identities’ is also recorded in the EA study where research participants from diverse minority ethnic groups referred to a lack of access to disability organisations, as well as a lack of access as disabled people within organisations promoting the rights of minority ethnic groups.

Suppression of identities, stereotyping by social expectations, various exclusionary forces impacting on everyday life and the invisibility of one’s identity within apparent safe spaces of social groupings or movements inform and influence the lives of individuals. This top-heavy declaration of ‘otherness’, however, is not the end of the story.

8.2.3 The Importance of Self-Recognition

The NIHRC research highlights the difficulty of ‘coming out’ for young lesbians, gays and bisexuals. As one participant remarked, *‘young people have to face the same difficulties as other teenagers and on top of that the issue of coming out’* (95). And as another said, *‘I worry; will my parents kick me out when they find out’* (95). And yet still another declared: *‘When you are gay, you have to mature more quickly; you have to learn to grow up’* (95).

The courage of young people who come out - whether to themselves, family and/or the wider society - challenges perceptions that there is only one way to be young and sexual. It is indicative of a resistance to how society describes the ‘normal’ young person.

The ECNI study provides a profile of comparable strength as it documents the choices of a disabled woman who is a mother: “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” (81). Here is a portrait of a self-defining woman passing on her freedom to break social patterns of exclusion to her children.

Sometimes the voices of those who are re-defining a positive sense of self become a vital resource for the social groups to which they belong. The EA study records the experience of a Deaf participant who was involved with the Deaf community:

“In alliance with the Deaf community, he was active in challenging prejudice and discrimination against Deaf people and promoting non-discriminatory forms of education and services for Deaf people. At the same time, he was active in challenging the Deaf community and clubs in Ireland to recognise diversity and to tackle racism among Deaf people and organisations” (17).

Those contesting society’s imposed stereotypes of who they are carry the potential to challenge various patterns of oppression (such as racism, disablism, homophobia, sexism) within many groups. In this way, they participate in breaking patterns of discrimination precisely through willingness to claim their multiple identities.

The struggle to resist stereotyping and the creative forces this unleashes comes through again in the narratives of Black and minority ethnic women. As the EOC study points out, many of the participants in their research are often not seen as individuals. They are perceived, instead in what the authors call a ‘gendered racial category.’ This means that they are stereotyped and demeaned by virtue of their gender *and* race. This kind of naming has included, ‘subservient Muslim woman’, ‘single, Black woman’ or ‘undeserving refugee woman.’ The study goes on to document, however, many examples of what they call ‘women’s other ways of knowing’ and their strategies to deal with the health inequalities that they encounter in their day-to-day lives.

“The women employed strategies to get around the health system. These were not simply ‘coping strategies’, but were grounded in self actualisation and real knowledge derived from their lived realities of racial and gender exclusions [. . .] The women’s narratives tell about being strong, brave, clever and dignified in the face of others perceptions of them as strange, stupid, manipulative or voiceless victims” (34).

Sometimes the women’s strategies focused on challenging the injustice of systems that see them as ‘the problem’. The study records a case where a Black British woman had to take her son several times to the hospital’s Accident and Emergency department to have him disagnosed, and for doctors to take his condition seriously. Her son had meningitis. Other strategies included drawing on folk knowledge, holistic and home remedies and alternative health cures that come from their cultures of origin. In these ways, women took control over their lives and well-being as they resisted the racism and sexism of the health systems. As an African born Goan living in Britain for 32 years said, *‘We’ve learnt from our mothers how to treat our colds and flus – we take ginger and cumin and whatever else we know we should – it is much better than going to the doctor’* (36).

These are just some stories, from diverse backgrounds, of people who are breaking oppressive social patterns as they ‘come out’, make positive choices for themselves and their children, and call for the diversification of cultural norms.

8.2.4 The Importance of Social Identity

While multiple identities of *individuals* was the research focus, an underlying theme was that the personal characteristics of individual identity hold *social* significance. This is so in at least two ways. Firstly, societies respond to individuals differently in light of the personal characteristics that they hold. Social relations develop in such a way that women are treated differently than men, minority ethnic groups are treated differently than majority ethnic groups, disabled people are treated differently than non-disabled people. The personal characteristics of individuals mean that they partake in the history of how societies have responded to these factors of identity. So, some people will experience the disadvantage and exclusion of, for example, sexism, racism and disablism of a society while others will not. Secondly, the personal characteristics of individuals determine their membership of social groups. Social groups such as women, disabled people, and lesbian, gay and bisexual people hold political importance in societies because they challenge how their members have been defined and treated, how power is organised and how social and economic benefits are distributed.

A key theme to emerge from this research is that people develop their identities in light of both individual characteristics they hold and social groups to which they belong. Identification with a social group often provides a positive sense of identity. The NIHRC study documents the isolation of young lesbian, gay and bisexual people in Northern Ireland and the importance of belonging to a group that affirms their youth and sexual orientation.

“Everyone in a focus group with Out and About (Youth Action Northern Ireland) agreed that they gained a great deal of support from meeting as a group twice a month. To their knowledge they are the only young lesbian support group in Northern Ireland. They felt there was a strong need for more support and information” (98).

Lesbian, gay and bisexual disabled people also registered strong feelings of isolation (DRC study). A key finding is that this isolation has to do with prejudice towards disabled people in the lesbian, gay and bisexual community and the existence of homophobia in the disability movement. Many lesbian, gay and bisexual disabled people do not feel comfortable in either the disability movement or the lesbian and gay community. Others may feel affirmed in one social group and disrespected in another. This points to the lack of recognising diversity within social groups and its negative consequences on a person’s self-esteem and individual identity. The study records how lesbian, gay and bisexual disabled people respond to this by forming their own informal networks.

'Most of us create our own community. I became disabled and was shunned by the lesbian community. They [other lesbians] have this fear that it [disability] might happen to them. It's essential [to see other LGB disabled people]. To be in a group where you don't have to explain yourself' (58).

The EA study confirms that identity is clearly related to belonging to a social group, and that the lack of a hospitable grouping can exacerbate one's experience of isolation. A minority ethnic person with a disability participating in the research expressed a strong desire to meet with others in disability organisations:

'I would love that. I would find more information. I would see the problems with other people. I feel rejected sometimes. Because they give you disability allowance and that's it. I feel completely like somebody that nobody wants. It is a need for people to socialise together' (10).

Yet, disabled people remain an almost invisible sub-group within minority ethnic communities in Ireland and many of the participants in the study on minority ethnic people with disabilities were unaware of the existence of organisations of people with disabilities.

Sometimes research participants resisted the language associated with social categories. Stereotyping and devaluing of certain social groups were reasons for this resistance. The CRE study concludes that young minority ethnic men did not like addressing issues or problems in terms of identity. Some argued that "dwelling on their ethnicity or religion would *'reinforce the stereotypes about these groups'*, which they themselves personally did not feel an association with. The young people we interviewed wanted to describe themselves and their experiences without labeling" (124).

The language used to articulate issues of identity was raised also in the EOC study. The women in this study did not use the 'equality discourse' of 'being women' or 'being Black'. Instead they talked about themselves as mothers, wives and being poor. "They talked about duty to the family, protecting their children, and surviving poor conditions, caring for others and organising for change" (41). They expressed themselves as whole human beings rather than 'a woman' in one circumstance and an 'African-Caribbean' in another.⁴ Their significant social groups were the communities of their own making. Their language was theirs and not the discourse of others.

An interesting theme to emerge, then, from several of the studies is that people with multiple identities are tentatively beginning to form new social networks or groups that reflect the diversity of identity.

8.3 DIVERSITY AND THE EXPERIENCE OF DISCRIMINATION

8.3.1 Attitudinal Barriers

People can meet prejudice on the basis of a single aspect of identity, for example, being disabled. The studies in this joint project, however, show that people with multiple identities encounter acute prejudice in their interactions with the health sector. Prejudicial attitudes cause harm or injury because they reflect intolerance towards others and assume that they are socially inferior or ‘abnormal’. The NIHRC research recounts several examples of prejudice towards young lesbian, gay or bisexual people in their experiences with the health care system.

“Several of them recounted that their GPs were judgmental about their sexual orientation. One young woman reported that her doctor said to her that “Gay people go to hell”, that he “outed her” to her family and wanted to book her in to see a psychiatrist. *‘I felt guilty to be gay and depressed. So I went to see another doctor. But he was also making comments and I was still depressed’* (99).

The study states that this behaviour is a breach of the young person’s human rights to privacy and confidentiality, protected by human rights law.⁵ The harm done here by judgement about sexual orientation is compounded by the fact that young people often are still under the guardianship of their parents or family. In another example from the same study it was reported that *‘Blood transfusion services do not take blood from gay men and this contributes to stigmatising [...] Gay men are still perceived as carrying HIV’* (99).

Disabled women in the ECNI study also encountered grave prejudice in their attempts to access health services. Negative attitudes were a major barrier to receiving appropriate health care. In documenting one woman’s story the study notes that she 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. She described this treatment as patronising: *‘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’* (78). Prejudice of this sort holds the potential to be life threatening for a disabled woman.

The DRC research also refers to the issue of motherhood for disabled women and notes that it is judged often as ‘strictly off limits’. The study discusses the existence of prejudice in the National Health Service regarding lesbian, gay and bisexual disabled people. Health professionals interviewed acknowledged that there is likely to be some prejudice for being either lesbian, gay and bisexual or disabled and, in some cases for both these reasons. One of the gay disabled participants of the same study had this to say:

‘A lot of issues [with healthcare provision] are linked to information. The GP just wouldn’t ask about your sexuality because [the GP thinks] disabled people don’t have

sex. If you were to announce 'I'm gay' they would probably just think that you were having an identity crisis, you were schizophrenic or seeking attention! And it would definitely be marked on your notes as that. I always tell people not to come out to their GP. They can then use it against you. It can affect housing benefit and incapacity benefit' (53).

This story hints at the social and economic impact of prejudice, as well as the emotional and personal costs. It makes visible links between economic inequality and low social status.

The EOC analysis refers to a similar dynamic between prejudicial attitudes and exclusion from adequate health services. The authors speak about the 'racialisation of health issues' or the in-built, yet subtle racism of health practices. They examine how sexist and racist attitudes intersect and argue that 'when a woman enters a doctor's surgery she is preceded by racial stereotypes.' Some of the health professionals in this study describe how pervasive this way of thinking is in the health service:

'I think there are very unsympathetic doctors out there – I think if you come in as the stereotypical image of being single and having children by more than one father and have limited English I think that the service is probably diabolical' (31).

'We see some Black and ethnic minority families having so many children - maybe they have three under the age of 5 - we perceive it as a problem . . . but maybe they don't - it's more natural for them to have larger families . . . we make assumptions of what is right and wrong' (31).

These accounts, and others throughout the joint research, exemplify harmful attitudes that often lead to exclusionary practices. Disrespecting individuals on the basis of two or more aspects of their identity creates substantial barriers for their health and well being.

8.3.2 Systemic Barriers

The research studies contain numerous examples of how current systems block people's participation in and benefit from the health sector. This concluding chapter highlights some of them. For example, the NIHR study asserts that

"There is an assumption that everyone is heterosexual and when it is otherwise young people have to identify as gay/lesbian/bisexual to access health services, especially sexual health. Health professionals in the focus group felt that the system is built in a way that forces gay, lesbian and bisexual people to come out. This is not expected of young heterosexual people. 'Doctors assume you are straight, you have to out yourself' " (100).

The study argues that inaccessibility to health services is because practices are not designed for people who differ from the dominant norm of heterosexual orientation.

Inequalities exist because practices *are not designed* to offer sexual health services on the basis of young people's diverse ways of being sexual.

The DRC study on lesbian, gay and bisexual disabled people concludes that "Sex education is wholly inadequate and fails to address issues of difference - both in terms of sexual orientation and implications of impairment" (62). Lesbian, gay and bisexual disabled people not only continue to face environmental barriers because systems, buildings, and practices *are not designed* with them in mind, but they are also blocked in their development as sexual beings because health educational services discount them.

The ECNI research on disabled women refers to examples of the inaccessibility of a bed or couch in doctors' surgeries for postnatal check-ups. In these instances barriers to appropriate health care are due to systems designed by people who fail to picture the presence of disabled women.

Both the EA and the EOC studies refer to the 'institutionalisation of racism' as a key factor causing discrimination in the health sector. Racism becomes institutionalised when "things are done in a way which assumes that all clients are from the same background as the majority population" (17). The assumption of sameness renders those who are not the same as the majority invisible or 'atypical' users in health and disability services. The EA study highlights two examples in this regard. In the first instance, "a health service worker pointed out that Traveller families may face particular obstacles to accessing residential or respite care for disabled children because of stereotypical views of Traveller behaviour" (18). In the second instance it notes that "some disabled minority ethnic people may be reluctant to approach health and disability services because of uncertainty about their citizenship status or that they face added difficulties due to separation from their families" (19). The presumptions of sameness appear to be foundations for the way things are normally done.

The EOC research 'maps the process of exclusion in the health service' for Black and minority ethnic women *in spite of* "a conscious adoption of a discourse on equality and anti-discrimination" (37). The study records narratives of women African Caribbean health workers who are blocked in their employment opportunities on the basis of their identities. Though stated equality policies exist, the women's stories reflect an absence of practice: *'opportunities are not equal here for workers or service users . . . promotion is never fair in terms of Black women'* (38).

This woman tells her story of applying for a study leave and how she is blocked by "the official criteria of 'no precedent, no special treatment' [that] failed to acknowledge her identity and duties as breadwinner and mother:

'They [the employers] give options of unpaid leave – but how can I study without a salary – and run my family home with no money.. we don't get rewarded for our desire

to improve ourselves – I wanted to do a course that would really help my work – but I wasn't allowed – I was told it would set up a precedent – and that was the end of that' (39).

Here is another example of how everyday practices in the health sector do not make room for the everyday realities of some people's lives. In this case, assumptions made in employment practices about the identity of all workers block equal opportunities for some.

8.4 IMPLICATIONS – THINKING ABOUT DIVERSITY

This research project has explored the reality of diversity in people's identity. Common issues surface in this joint piece of work. The research depicts how people's identities are multiple, changing and at times imbued with contradiction. The studies document that people who hold multiple identities experience acute prejudicial attitudes and disrespect. The reports highlight the importance of self-recognition, social identity, resistance of stereotypes and labels, and alternative strategies developed by people to cope with multiple inequalities. There are numerous examples of how current systems block people's participation in and benefit from the health sector. Multiple barriers to equality exist for people who participated in these studies. Lack of recognition of their diversity happens not only in systems of service provision, but also within social groups and community and voluntary organisations.

These findings offer a new platform from which to think about the core principle of 'diversity' in the work of equality and human rights bodies. People have a right to be different because they are different. Societies' response to difference in people's identities creates the conditions for how they access and participate in social and economic resources, for how they are included or excluded, oppressed or free. People's differences are complex. The complexity of people's identities - particularly the inter-relation of personal characteristics with social significance - shapes the complexity of how they experience discrimination, oppression and inequality. The research documents how combinations of various oppressions together produce something quite unique. It may be helpful then, to outline an understanding of diversity that takes account of these findings.

8.4.1 Domains of Diversity

There are four domains within which it is important to understand diversity:

- the individual
- social groups
- social relations
- institutions

The Individual – Assume Differences Within

Conducting a systematic exploration of people's multiple identities provides a picture of individuals as they really are. Individuals do not fit into one neat box of being a 'woman', 'disabled' or 'lesbian' person. Taking a 'multiple identities' focus offers a more holistic understanding of the diversity within individuals and how they experience barriers to equality and discrimination in light of this. All individuals hold multiple identities, but the social significance of personal characteristics is what can determine their experience of equality or inequality, the fulfillment or violation of human rights. The multiple identities of individuals shape their experience of discrimination. Without an *assumption of the differences* within individuals, there is a failure to understand the complexity of how people genuinely experience discrimination, a violation of rights and barriers to equality. Grounds for discrimination cannot be viewed as rigid, watertight compartments. Many people will experience 'intersectional discrimination' based on two or more characteristics of their identity.

Social Groups – Examine Differences Within

This research highlights the significance of social groups in the shaping of a person's identity. Concrete documentation and analysis of people's multiple identities demonstrates the need for an ongoing *examination of differences* within social groupings. Acknowledgement *and understanding* of diversity within social groups is critical not only for a more accurate representation of the position of these groups within society, it is also crucial for the creation of positive environments for the personal development of those who belong to these groups. Such examination may allow for the emergence of new social groupings or networks, as demonstrated in the research. Or it may establish an ongoing mechanism for analysis of the inter-relation of personal characteristics and how this shapes personal identity and social position.

Social Relations – Analyse Intersections Between

Relations between social groups shape how differences between people are perceived and treated, how power is organised in societies, and how societies distribute their resources. Social relations have often resulted in the oppression of some groups because of their assumed inferior status or existence outside of what is defined as 'normal.' Sexism, racism, disablism, ageism and heterosexism are some of the terms that depict these unequal relations between different social groups. They are terms that reflect the denial of diversity.

Given an individual's multiple characteristics, she or he may be impacted by the history of social relations between several groups. Within one individual the forces of sexism and racism can intersect, or disablism and heterosexism can become intertwined. Acknowledging diversity requires then a thoroughgoing analysis of the intersections of unequal social relations. This can be done through theoretical investigations and/or a continued research focus on 'multiple identities'. Analysis of intersections may yield more clarity in understanding the root causes of inequalities across social groups.

Institutions – Apply an Integrated Approach

This research identifies an institutional failure to provide appropriate and professional health services to people of particular multiple identities because of their increased vulnerability or marginalisation. It outlines attitudes, processes and behaviour that disadvantage people on the basis of their combined personal characteristics. This amounts to unique experiences of discrimination and unequal access based on an intersection of grounds.

The institutional domain poses perhaps the greatest challenge to understanding and accommodating the full complexity of human diversity. It requires a re-think of equality and diversity policies that incorporates an integrated approach. Such an approach is first of all based on the assumption that individuals have multiple identities. Secondly it analyses service and employment systems from the perspective of intersecting personal characteristics. While this may seem an awesome task, its practical implementation may benefit from research that identifies the experiences and aspirations of multiple identity groupings, and research on the identities of those who use the services or who are employed by them. This can provide a starting point for developing a mindset of integrated diversity, and bringing this to bear on system design and professional attitude and behaviour.

8.5 NEXT STEPS

Making diversity visible and thinking about diversity in new ways suggest that some things be done differently. The studies in this report lead to a number of practical implications for the health sector, voluntary sector and equality and human rights bodies.

8.5.1 Diversity and the Health Sector

Equality practices in the health sector need to be re-assessed from the perspective of how diversity is recognised and dealt with. There needs to be more awareness of the cultural norms informing organisational structures and work practices, as well as openness to challenging prejudicial and disrespectful attitudes.

Equality and Diversity Training

Mainstream training for health service professionals needs to encompass awareness that people can hold multiple identities. Equality training specialising in one social ground, for example disability, could include attention to other grounds such as sexual orientation. The DRC study on lesbian, gay and bisexual disabled people recommends that the design of diversity training and information resources for health professionals should be a next step for the DRC in conjunction with Stonewall and self-help groups of lesbian, gay and bisexual disabled people.

Sensitivity training is also critical for raising equality issues as an initial step towards change. It could usefully examine and make explicit prejudicial and disrespectful attitudes that health service providers can hold, as documented in a number of the research studies. This training could develop awareness about prejudices in relation to the diversity of people within recognised social groupings. The EOC study noted the interplay of sexist and racist attitudes held by professionals in the National Health Service. These attitudes block them taking into account the requirements of women who do not come from the dominant culture. The EA study suggests that health and disability services need to develop the capacity to address racist practices and prejudice among staff in their organisations. This would begin to reduce barriers that disabled minority ethnic people face in accessing health and disability services. The NIHR report recommended that medical staff should be trained in the needs of young lesbian, gay and bisexual people and that this training addresses the prejudices and stereotyping facing them. This could be designed as specialised training or mainstreamed into the training on the needs of young people.

Mainstreaming Diversity

Mainstreaming has to do with incorporating equality objectives into policy design, implementation and assessment. While health services may be developing equality policies that influence work practices and delivery of services, these need to be proofed for diversity awareness. Decisions need to be made and resources allocated to ensure that all social groups and *diversity within social groups* are adequately reflected so all people have equal access to services and employment.

The ECNI study suggests that equality strategies in the health sector should improve awareness of issues specific to disabled people in general and disabled women in particular. It is a matter of urgency that health providers make reasonable adjustments to physical features of services for disabled women. Maternity services, for example, should take account of the needs of women in all their diversity. The NIHR report recommends that health service providers have to examine the needs of people with multiple identities as they draw up and implement Equality Schemes. They need to avoid the trap of considering the nine groups specified in Section 75 in isolation.⁶ Equality issues for young lesbian, gay and bisexual people are at the intersection of several categories such as sexual orientation, age, gender and disability.

The EOC study suggests a re-assessment of policies for setting targets. If targets for homogeneous social groups are set, how inclusive are these for the diversity of individuals within those groups? The EA report suggests that equality practices in the recruitment of employees as well as in the workplace need to take account of the fact that employees or potential employees may differ on more than one equality ground. Otherwise, equality for disabled minority ethnic people is not likely to be achieved.

Information Provision

Access to information about health services is vital for people's equal participation and benefit. This involves producing appropriate information according to individual and social group differences. It also means ensuring that information is available in places where people will find it. The EA study observes that lack of information is a key barrier preventing disabled minority ethnic people from accessing health and disability services. A research participant recommended setting up an information centre for asylum seekers and refugees with disabilities, and providing information packs on services available. The NIHR report recommended that health professionals work with voluntary organisations to disseminate information on sex and health education for young lesbian, gay and bisexual people. If posters and leaflets were available in GP surgeries it would make it easier for young lesbian, gay and bisexual people to engage with doctors. These are just two examples of designing and disseminating information geared toward people holding multiple identities.

8.5.2 Diversity and the Community and Voluntary Sector

Community and voluntary organisations representing interests of different social groups are vital agents for promoting equality in societies. Their activities make group differences visible thus challenging social patterns of oppression and exclusion such as disability, heterosexism, racism and sexism. They often provide communities and safe environments for people to shape a positive sense of identity. Many of the studies in this project record the significance of networks, communities and representative organisations for research participants.

Diversity Awareness

While there is a growing awareness among community and voluntary organisations of the need to embrace diversity, the research documents that many people face barriers to engaging with them. Participants in the DRC research talked about the homophobia in disability organisations and disability in lesbian, gay and bisexual communities. The study recommends building the capacity of grassroots networks of lesbian, gay and bisexual disabled people and that established lesbian, gay and bisexual organisations should take into account the needs and aspirations of disabled people. Participants from new minority ethnic communities in the EA study expressed a strong desire to meet with other disabled people and to be involved in disability organisations. Community and voluntary organisations representing disabled people could develop initiatives to include people from minority ethnic groups. Groups representing minority ethnic people could take account of issues facing disabled people in their communities. In addition, consideration could be given to the establishment of a new association of disabled minority ethnic people.

Reports in this joint project also affirmed voluntary effort that provided important group support. The CRE study documented the substantial assistance given to young Black (African-Caribbean) men in a project sponsored by a young people's charity. The project

enables the men to challenge negative views and stereotyping of themselves and their local community. The NIHRC research acknowledged the important role played by lesbian, gay and bisexual organisations in providing support and information to young people, and recommended that they be properly funded. All studies point to the need for community and voluntary organisations to generate diversity awareness within their social groupings.

Promoting Solidarity across Social Groups

Community and voluntary organisations representative of distinctive social groups are in a unique position to promote solidarity across the groupings, thereby providing another avenue to acknowledge and understand the dynamics of people's multiple identities. A concrete way in which this could be done is for a number of organisations to engage together in an analysis of the common causes of oppression and discrimination that their members experience. This holds the potential to develop a common framework to analyse what is wrong, so that integrative solutions may be found. To embark on such an initiative involves each social grouping accepting the challenge to broaden its lens beyond its own distinctive experience of discrimination. While this involves risk, it holds potential to practice new configurations of solidarity and collective advocacy in order to shift current practices and policies.⁷

8.5.3 Diversity and Equality and Human Rights Bodies

Promoting equality and human rights is the responsibility of all members of the Joint Equality and Human Rights Forum that commissioned this research. The joint project itself is an exercise in raising awareness about diversity and engaging in cross-ground work within their respective mandates. The research findings have identified a number of equality and human rights issues that relate to the multiple identity groupings studied, and which deserve consideration by the various equality bodies. The findings also provide a new platform from which to deepen an understanding of the full complexity of 'diversity' as a core principle in equality and human rights work. Equality and human rights bodies need to consider the various 'domains of diversity' identified and investigate ways to utilise this framework in the future. Some of the following steps may assist this process.

Legislation

Studies conducted in Great Britain and Northern Ireland highlight the need to address current equality legislation that provides different rights on different grounds so that some groups receive better protection than others do. The EOC study points out that Black and minority ethnic women often fall between the legislative provision for race and sex, and are rarely able to make multiple discrimination claims. The ECNI report discusses a 'hierarchy of discrimination' that disabled women experience, indicating the lack of equivalent anti-discrimination protection on the grounds of disability and gender. People with multiple identities, therefore, are not adequately protected by current legislation. These findings add strength to the argument that there is a need in these jurisdictions to harmonise anti-discrimination legislative provisions by levelling up

people's rights and protections. Equality and human rights bodies can be strong advocates in this regard, especially in their responsibilities to review equality and human rights legislation.

Even with harmonised legislation, people with multiple identities that increase their social vulnerability and marginalisation may require an 'intersectional approach' to equality and human rights claims. This is an approach being developed that takes due account of a complaint on the basis of multiple grounds of discrimination. This approach has been defined as 'taking account of the historical, social and political context, and recognising the unique experience of the individual based on the intersection of all relevant grounds.'⁸ The most common approach to discrimination claims is one that tends to focus on a single ground. Equality and human rights bodies need to take account of developments in this area and investigate ways of incorporating such an approach in their own work.

Equality Data

Absence of data across social groups and protected grounds is a significant barrier in assessing the impact and quality of equality and human rights strategies. Three studies in this report - the EOC, the CRE and the ECNI - present some statistics on the situation of people with multiple identities. The DRC, EA and NIHRC studies refer to the lack of data available. Reports recommend that health and other services need to gather data relating to the diversity of grounds in order to plan and monitor more accessible and effective services. Equality and human rights bodies play an important role in advocating progress in this regard.

Equality Schemes, Reviews and Standards

Equality and human rights bodies often hold responsibility for promoting or monitoring equality schemes for public sector bodies, employers, government departments and local authorities. These schemes, standards or reviews are being developed to mainstream equality objectives and targets across a range of social groups and protected grounds within institutions. As this work develops, it will be important to build in specific mechanisms for ensuring ways of dealing with the inter-relationship of equality issues for people who experience increased disadvantage and vulnerability because of their multiple identities.

Research and Communication

Research and Communication strategies are key areas of work for equality and human rights bodies. Research strategies could include a cross-ground strand as well as ensuring that research in service provision and employment investigates diversity issues within social groupings. Communication strategies hold considerable potential to raise awareness about diversity in people's identities. As the CRE study points out, popular media plays a role in promoting stereotypes and negative images of minority groups within society. This can be challenged by positive images of people belonging to less

visible social groups, and images of people holding multiple identities. Communicating diversity includes both.

8.6 CONCLUSION

The challenge of diversity to equality and human rights work is substantial. It requires a paradigm shift of sorts in ways of thinking about different groups in society and differences within those groups. It necessitates changes in attitudes and systems to root out all forms of institutional discrimination. It calls for ongoing analysis of how patterns of social relations intersect to exclude and discriminate against members of society. Investigating the multiple identities of individuals is a useful step in this direction of social change.

NOTES

- 1 See Zappone, K.E.(2001) Charting the Equality Agenda. A Coherent Framework for Equality Strategies in Ireland North and South, the Equality Authority and Equality Commission, for a detailed development of this argument. In advancing a more nuanced understanding of diversity, though, it is important to maintain awareness that discrimination on the basis of differences between social groups is still prevalent.
- 2 Researchers recognised that people have other aspects to their identities, but this project did not set out to explore these additional variables.
- 3 Several theorists speak about the experience of contradiction in identity - negation on the one hand and affirmation on the other.
- 4 The EA study refers to the concern by some theorists that the concept of 'multiple identities' will lead to a process of fragmentation in people's lives. They could be seen simply as the product of two or more characteristics. Instead, other theorists argue that people can develop a 'unified sense of self even though they have more than one identity' (p. 7). The women in the EOC (GB) study appear to express this unified sense of self.
- 5 See article 16 of the UN Convention on the rights of the Child.
- 6 In Northern Ireland public authorities are under a statutory duty to promote equality in terms of employment and service provision and consequently are compelled to produce an Equality Scheme. This statutory duty is outlined in Section 75 of the Northern Ireland Act, 1998.
- 7 See Zappone (2001), p. 88 for guidelines to conduct such an analysis.
- 8 Ontario Human Rights Commission (2003), 'An Intersectional approach to

Discrimination: Addressing Multiple Grounds in Human Rights Claims', p. 3. This discussion paper, recently issued, provides a very fine analysis of the rationale for and movement towards an intersectional approach in dealing with human rights claims by reviewing national and international jurisprudence that is developing in this regard.

CONTRIBUTORS

Katherine Zappone PhD is an independent consultant and a member of the Human Rights Commission, Ireland.

Maria Pierce is the Research and Teaching Fellow in the Department of Social Policy and Social Work, University College Dublin. She has worked in the voluntary sector and has experience as a researcher in the areas of gender equality, lone parents and the delivery of social and information services at local level.

Heidi Safia Mirza is Professor of Racial Studies at Middlesex University. She established the Centre for Racial Equality Studies as a Centre of Excellence for the promotion of race and gender research at the University and has written extensively on identity, ethnicity and gender issues.

Ann-Marie Sheridan is a researcher at the Centre for Racial Equality Studies at Middlesex University.

Michael Brothers is Special Projects and Co-ordination Manager with the Disability Rights Commission (GB). He is also responsible for the Joint Equality and Human Rights Forum's Secretariat.

Norrie Breslin is employed as a Research Officer in the Equality Commission for Northern Ireland. She has previously been employed in public sector housing research and in an academic environment researching participation in further and higher education.

Christine Loudes has completed a doctorate in law in the Queen's University of Belfast on the subject of women's political representation in international, French and British law. In January 2001 she joined the Northern Ireland Human Rights Commission as an investigations worker.

Colin Hann is a senior partner at MDA, a diversity and research consultancy, and also a partner at Article 13.net a European diversity consultancy group. Before then he worked at top City and European law firm DLA. Colin also previously worked at the CRE, where he was Director of Communications and Strategy. Colin was assisted on this project by Rajwant Bains, an associate at MDA.

CONTACT DETAILS

Equality Authority

2 Clonmel Street
Dublin 2
Lo Call: 1890 245 545
Tel: 01 417 3333
Fax: 01 417 3366
e-mail: info@equality.ie
website: www.equality.ie

Equal Opportunities Commission

Arndale House
Arndale Centre
Manchester
M4 3EQ
Tel: 0845 601 5901
Fax: 0161 838 1733

Disability Rights Commission

Freepost MID02164
Stratford upon Avon
CV37 9BR
Tel: 08457 622 633
Fax: 08457 778 878

Equality Commission for Northern Ireland

Equality House
7-9 Shaftsbury Square
Belfast
BT2 7DP
Tel: 028 60 500600
Fax: 028 90 248687

Northern Ireland Human Rights Commission

Temple Court
39 North Street
Belfast
BT1 1NA
Tel: 028 9024 3987
Fax: 028 9024 7844

Commission for Racial Equality

St. Dunstan's House
201-211 Borough High Street
London
SE1 1GZ
Tel: 020 7939 0000
Fax: 020 7939 0001

Human Rights Commission

17-19 Lower Hatch Street, Dublin 2
Tel: 01 6472562
Fax: 01 6472515
email: ihrc@eircom.net

