Equality Research Series



# Minority Ethnic People with Disabilities in Ireland

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Minority Ethnic People with Disabilities in Ireland

Situation, Identity and Experience

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# FOREWORD

This study on minority ethnic people with disabilities breaks important new ground with its focus on those people at the intersections of two groups - minority ethnic people and people with disabilities - which are all too often seen as distinct and separate. Minority ethnic people with disabilities emerge from this study as a group with their own distinct identity, experiences and situation, a group exposed to multiple discriminations based on racism and disabilism, and a group that poses very particular challenges to the design and implementation of equality strategies by employers and service providers.

This study draws on previous work carried out by the Equality Authority in partnership with the Equality Commission for Northern Ireland (Zappone, 2001). This work identified the need for equality bodies with a mandate that covers a wide range of different discriminatory grounds, to work at three different levels:

- developing initiatives that have a relevance and bring benefit to all grounds covered under the legislation
- taking action that focuses on a single ground where issues specific to that ground arise
- opening up work on issues for people at the intersections of different grounds such as minority ethnic people with disabilities, people in other words who experience multiple discrimination

This latter area of work – seeking to address multiple discrimination – poses very particular challenges to equality strategies that seek to combat all forms of discrimination, to accommodate diversity and to promote equality outcomes. Meeting these challenges demands a greater knowledge of the situation, experience and identity of groups such as minority ethnic people with disabilities. This is the inspiration for this study.

There is of course a significant academic dimension to a study such as this that seeks to break new ground. Equally there is a vital practice dimension. This study needs to inform and shape:

- service provision targeting people with disabilities on the basis of standards set that ensure cultural diversity is acknowledged, valued and taken into account in the design and delivery of such services
- initiatives being taken to secure an inclusion for black and minority ethnic people (including Travellers) on the basis of standards that ensure a reasonable accommodation for minority ethnic people with disabilities within these initiatives
- the management of diversity in employment settings and in mainstream service provision on the basis of standards that take account of the multiple identities that people hold

This study has been prepared as part of a wider body of work developed with the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission, the Irish Human Rights Commission, the Disability Rights Commission (GB), the Equal Opportunities Commission (GB), and the Commission for Racial Equality (GB). This wide partnership with a shared focus on issues of multiple discrimination has allowed the development of a significant body of work on the experience, situation and identity of a broad range of multiple identity groupings. A compilation of this work has been published separately (Zappone, 2003).

We are grateful to Maria Pierce for her patient, thorough and professional approach to the preparation and drafting of this study. She has made a valuable contribution to the gradual emergence of new evolved equality strategies with a capacity to be inclusive and comprehensive.

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Niall Crowley Chief Executive Officer Equality Authority September 2003

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# INTRODUCTION

### 1.1 Background and Research Focus

This report is about the situation, identity and experiences of black and minority ethnic people with disabilities in Ireland. It is a small-scale, exploratory research study and was commissioned by the Equality Authority in May 2002. The study is one of six related projects. The six studies form part of a joint research project of the Joint Equality and Human Rights Forum, which aimed to explore the reality of diversity in people's identity. The Forum comprises the Equality Authority (Republic of Ireland), the Commission for Racial Equality (GB), the Disability Rights Commission (GB), the Equal Opportunities Commission (GB), the Northern Ireland Human Rights Commission, the Equality Commission for Northern Ireland and the Human Rights Commission (Republic of Ireland). The project was co-ordinated by the Equality Authority.

As part of the joint research project, each of the members of the Forum undertook to conduct, or engage a researcher to conduct, a separate study on the situation, identity and experiences of people in a particular multiple identity grouping. This study commissioned by the Equality Authority focuses on the situation, identity and experience of minority ethnic people with disabilities in Ireland. The situation, identity and experiences of people in different multiple identity groupings were explored by other equality and human rights institutions involved in the Joint Equality and Human Rights Forum research project and a compilation of this work has been published separately (Zappone, 2003) – see Table 1.1.

Equality/Human Rights Body	Multiple Identity Grouping	
Equality Authority (IRL)	Black and minority ethnic people with disabilities in Ireland	
Equal Opportunities Commission (GB)	Black and minority ethnic women in Britain	
Disability Rights Commission (GB)	Disabled lesbian, gay and bisexual people in Britain	
Equality Commission for Northern Ireland	Disabled women in Northern Ireland	
Northern Ireland Human Rights Commission	Young lesbian, gay and bisexual people in Northern Ireland	
Commission for Racial Equality (GB)	Young minority ethnic men in Britain	

Table 1.1 Joint Ed	quality and Hu	man Rights Forum	<b>Research Project</b>
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The primary focus of the research was to investigate how individuals holding multiple identities understand their identities and sense of belonging to different social groupings. In addition, the studies examined the experiences that these individuals had of accessing public services in the health sector.

The health sector was chosen in order to achieve consistency across the research projects. The experiences of individuals in participating in employment was also examined in some of the studies. The six related studies came about as a response to work carried out by Zappone (2001) published jointly by the Equality Authority and the Equality Commission for Northern Ireland. The report examined the issue of multiple identity and explored the need for the development of activities that focus on cross-ground issues (that is, activities that reflect the multiple identities that people hold) in implementing an integrated approach to equality. Zappone pointed out, "there is little systematic research/analysis to date that documents the real and historical multiple identities of people in Ireland North and South" and suggested that there was a need to, "facilitate a multiple-discrimination analysis within social groupings" (2001: 89).

This is an exercise that involves identifying the primary multiple identity subgroups within a social grouping, gathering information on specific needs of these subgroups and setting out the changes necessary to address the inequalities resulting from multiple discrimination. Zappone also suggested designing a multi-focal tool with a lens for each protected social grouping for the equality assessment of policies, employment and service provision. This involves gathering data to a common template on each of the social groupings covered by equality legislation. This template addresses the situation, identity and experience of the group with a view to identifying common issues of concern. This study and the other related studies seek to build on, and further progress, this work.

The Equality Authority has previously been involved in work with a cross-ground focus. For example, it has been involved in an event to highlight, explore and debate the particular issues facing gays, lesbians and bisexuals with disabilities. Such a cross-ground focus is supported by other organisations in Ireland. The National Economic and Social Forum (NESF) considers that work with a cross-ground focus, "provides the potential to inject new creativity, new solidarity and new commitment in the pursuit of equality" (NESF, 2002: 34). Other Irish bodies such as the National Disability Authority and the National Consultative Committee on Racism and Interculturalism also support such an approach to equality.

In Ireland, there is, in general, a dearth of information on disability identity and how people with disabilities perceive and experience disability. In recent years, the experience of people with significant physical disabilities has been the subject of research in Ireland (Tubridy, 1996) and there is a growing body of literature on the subjective experience of people with physical disabilities in Ireland (Quin and Redmond, 1999). However, there is a tendency to view people with disabilities as one homogenous group. Studies concerning people with disabilities tend to reflect this.

In recent years there have been calls for greater attention to be paid to diversity and difference among people with disabilities. Shakespeare (1996) argues for a move away from the unitary essentialist disability identity and towards an understanding of disability in terms of variety of disability identities. It is increasingly recognised that people with disabilities cannot be seen as one unitary group. This is based on the recognition that a range of factors such as gender, class, sexuality and age structure the experience of people with disabilities. As Shakespeare puts it, "it is dangerous to overlook multiple identities, and to assume that disability is the sole and significant identity" (1996:110). The Equality Authority's involvement in an event concerning gays, lesbians and bisexuals with disabilities is an example of an approach that focuses on people with disabilities as a heterogeneous group.

The experiences of people with disabilities can be structured by ethnicity and racism. The need for a greater exploration of disability as it relates to ethnicity has been emphasised by a number of commentators. For example, Begum states that:

"there has been very little analysis of the experiences of black disabled people, or of the diverse and complicated issues which affect us. To avoid the dangers of feeding into cultural misunderstandings and racist stereotypes, we urgently need a thorough investigation of the experiences of black disabled people." (1992: 71) The significance of recognising diversity among people with disabilities is increasingly emphasised at European and international level. This study is consistent with the objectives of the European Year of People with Disabilities 2003, which aims 'to make people aware of the heterogeneity of people with disabilities and of people with disabilities facing multiple discrimination'. It is also consistent with the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which calls for special attention to be directed towards minority ethnic people with disabilities, migrant workers with disabilities and the large number of refugees with disabilities.

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. There are also other minority ethnic communities. These communities are made up of people who have come to Ireland as asylum seekers, refugees and migrant workers, and their families. Despite Ireland's ethnic diversity, there has been little or no analysis to date of the experiences of minority ethnic disabled people living in Ireland. Rather, people with disabilities within minority ethnic communities are often sidelined or ignored in studies relating to people with disabilities (McDonagh, 2002). This study goes some way to addressing this gap.

# 1.2 Study Methodology and Outline

The research has the following objectives:

- to examine the available research to identify equality and/or human rights issues with regards to minority ethnic people with disabilities
- to provide a profile of minority ethnic people with disabilities in Ireland
- to explore the experiences of minority ethnic people with disabilities and to examine implications of this identity in relation to equal opportunities and human rights
- to explore the barriers for people with this multiple identity to participating in employment and to accessing services, using the health services as an example for exploration
- to contribute to ongoing exploration of approaches to a multi-ground equality agenda

The research included documentary and qualitative research. The documentary component involved a review of relevant Irish, UK and international literature on issues relating to black and minority ethnic people with disabilities. This provided invaluable information for informing the fieldwork. The research aimed to provide a description of the social situation of black and minority ethnic people with a disability in Ireland. Data relating to minority ethnic people with disabilities is hard to obtain. Nonetheless, the research involved an examination of key statistical data in Ireland. The main objective was to identify gaps in existing national data and examine the potential of statistics for profiling minority ethnic people with disabilities and for equality monitoring with respect to this social grouping.

The fieldwork was based on in-depth one-to-one interviews. This took place between May and November 2002. When the research was commissioned, it was envisaged that focus groups would be used to explore the identity, situation and experiences of minority ethnic people with disabilities. However, minority ethnic people with disabilities have received little or no attention in Ireland to date and very little is known about them. They are, for the most part, an invisible group of people. There is currently no existing organisation or grouping of minority ethnic people with disabilities in Ireland. There is little awareness about and contact with minority ethnic people with disabilities among most minority ethnic groups, disability organisations and health services in Ireland.

A proposal was made to explore the identity, situation and experiences of minority ethnic people with disabilities through one-to-one in-depth interviews instead of focus groups. It was believed that this approach would better facilitate potential participants to participate in the research. This was

based on a concern that circumstances may create obstacles preventing potential participants from participating in focus groups. For instance, it seemed likely that due to their precarious circumstances and uncertainty about their status some asylum seekers with disabilities would be less reluctant to participate in one-to-one interviews than in focus groups with individuals with whom they had no previous contact. It was considered that one-to-one interviews were the most appropriate way to explore the experiences of minority ethnic people with disabilities, as it would not involve asking individuals with wide-ranging differences in terms of type and severity of impairment, gender, age, ethnic and cultural differences to come together and discuss their experiences of disability and ethnicity, which in turn were potentially very different. There would also be language and communication issues as well as physical barriers facing people with disabilities. Added to that was the possibility that potential participants would be widely dispersed throughout the country. Other factors included the relatively short time scale of the research and the timing of the research.

Qualitative one-to-one interviews were held with nine minority ethnic people with disabilities in Ireland to explore what it is like to be a person with disabilities in Ireland with a minority ethnic identity. Participants were accessed through a small number of voluntary and community groups, although a wide range of statutory and community and voluntary organisations were approached with a view to accessing participants for the research. The interviews investigated participants' experiences of multiple identities as well as their experiences in accessing health services and participants. Two interviews were mainly conducted in the homes or residences of participants. Two interviews lasted between three-quarters of an hour and three hours. When needed language interpreters, including sign language interpreters, were involved in the interview process. The views of service providers on barriers preventing minority ethnic people with disabilities from accessing health services were also sought.

The report that follows discusses the situation, identity and experiences of minority ethnic people with disabilities in Ireland.

Chapter 2 of the report is primarily concerned with socio-cultural inequalities between groups of people. Recognition of identity is central to an understanding of socio-cultural inequalities. The chapter explores the notion of social or group identity and the importance of recognition of identity for developing a positive group identity. It examines how misrecognition of identity can undermine a person's or group's sense of self and worth as well as the importance of a collective context for resisting negative constructions of identity. It goes on to explore the concept of multiple identities and its role in reflecting the complexity of people's identities.

The situation (or socio-economic profile) of minority ethnic people with disabilities is outlined in Chapter 3. The chapter highlights the difficulties that arise when trying to profile minority ethnic people with disabilities in Ireland. This is because they are an almost invisible sub-group within Irish society as well as within statistics. Key existing national statistics are examined and the potential of these important data sets for identifying minority ethnic people with disabilities with a view to equality monitoring is discussed.

Chapter 4 of the report explores the identity and experiences of people with disability from minority ethnic communities in Ireland. The chapter draws on interviews with nine minority ethnic people with disabilities living in Ireland. It explores their social identity, that is, how minority ethnic people with disabilities understand and perceive who they are. The key issues that arose during the interviews are discussed under the following headings: self-determination of identity; perceptions of disability among participants; ambivalent identities; autonomy, independence and control; exclusion; discrimination; and claiming 'other' identities. The section also explores issues of associational identity for minority ethnic people with disabilities in Ireland, that is, their identity with and experience of minority ethnic community groups and disability groups and organisations.

Chapter 5 also draws on interviews with the nine minority ethnic people with disabilities participating in the study. It explores what their experiences were of accessing health services. Some views of health services providers are included. The chapter also explores what their experiences were of participating in employment.

Finally, Chapter 6 draws conclusions from the research.

# EQUALITY: ISSUES OF DIFFERENCE AND IDENTITY

Ireland is a diverse society. There are wide ranging differences between people in Irish society in terms of gender, age, disability, ethnicity, religion, family status and sexual orientation. People in society are divided into *social categories* or *social groupings* according to such differences. For example, women and men are divided into categories according to gender differences. Several distinct categories may be used to denote differences between ethnic groups. The category disabled makes a distinction between 'able-bodied' people and 'dis-abled' people.

Inequality is one of the hallmarks of Irish society. The differences between groups of people in Irish society are marked by inequalities. This chapter is primarily concerned with socio-cultural inequalities between groups of people. Recognition of identity is central to an understanding of socio-cultural inequalities. It explores the notion of social or group identity and the importance of recognition of identity for developing a positive group identity. It examines how misrecognition of identity can undermine a person's or group's sense of self and worth as well as the importance of a collective context for resisting negative constructions of identity. It then goes on to explore the concept of multiple identities and its role in reflecting the complexity of people's identities.

However, before turning to look at socio-cultural inequalities between different groups, it would be useful to first examine material or socio-economic inequalities between groups of people in society.

### 2.1 Material or Socio-economic Inequalities Between Groups

Strategies to progress equality in Irish society include a focus on material or socio-economic inequalities. This relates to people's access to economic resources. In Ireland, as elsewhere, income from employment represents the major economic resource for day-to-day living. Other important dimensions include access to health and health care, education, housing and so on. Redistribution has emerged as a response to material inequalities and a means by which a more equal distribution of income and resources can be achieved in Irish society.

There are diverse socio-economic differences between groups of people in terms of gender, age, disability, ethnicity, religion, family status and sexual orientation. This can be illustrated by data showing patterns of inequality along group lines. For example, there is evidence of material inequalities between ethnic communities. The Labour Force Survey in the UK, which provides information on ethnicity and unemployment, has shown that unemployment is twice as high among minority ethnic groups, although it varies considerably between ethnic groups and by age and gender

(Levitas, 1996). Material inequalities between able-bodied people and people with disabilities also exist. In Britain, studies have shown that people with disabilities are less likely to be in paid work than adults in the general population (Abberley, 1996). Recent statistics indicate that a similar situation exists in Ireland (see Chapter 3). A clear example of health inequalities that exist along ethnic group lines in Ireland comes from research into the health status of the Traveller Community carried out in 1986 and 1987. Based on mortality and morbidity rates and ratios calculated on the vital statistics of one year, the Traveller Health Status Study demonstrated that Travellers of all ages have very high mortality rates compared to the Irish population (Barry, Herity and Solan, 1989). While no similar study has been carried out since 1987, research conducted in recent years suggests that the health status of Travellers has not improved and may have deteriorated (Quirke, 2002).

As well as differences between groups, there are important differences within groups. People from minority ethnic backgrounds differ on grounds such as gender, age, disability, religion, family status and sexual orientation. People with disabilities differ on grounds such as the nature of their impairment, gender, age, ethnicity, religion, family status and sexual orientation. The concept of 'double discrimination' has emerged to describe the experience of people who fall within two social groups and are confronted with more complex inequalities. This study focuses on one such group, that is, people with disabilities from minority ethnic communities. The experience of double discrimination by this group of people can be illustrated using data from the US, which relates to the area of employment. US Census Bureau's data (1994-1995) shows that, for people of working age with disabilities, unemployment is highest among minority ethnic people with disabilities: 72.2% of African Americans with disabilities and 51.9% of Hispanics with disabilities are not working compared to 48% of all persons with disabilities (cited in Simpson, 1999). For those with severe impairments the situation is worse.

The material inequalities facing women and other social groups such as the Traveller community and people with disabilities in Irish society has been acknowledged in the reports of commissions and task forces appointed by government. The Report of the Second Commission on the Status of Women (Government of Ireland, 1993) provided a comprehensive review of the unequal status of women in political, social and economic life in Ireland. The Report of the Task Force on the Travelling Community (Government of Ireland, 1995) placed a strong emphasis on addressing inequalities encountered by Travellers. The Commission on the Status of People with Disabilities (1996) described the overall situation and service provision for people with disabilities in Ireland. The reports highlight the need for a redistribution of social and economic resources in order to reduce or eliminate material inequalities encountered by such groups and to progress equality.

# 2.2 Socio-Cultural Inequalities Between Groups of People

The reduction of patterns of material inequalities is an important goal of equality strategies. However, it is increasingly argued that an understanding of equality also requires a focus on socio-cultural inequalities. Socio-cultural inequalities, which are intertwined with material inequalities in society, are rooted in patterns of representation, interpretation and communication (Fraser, 1995). The notion of recognition is central to the idea of social-cultural inequalities.

One approach to recognition is based on identity, which Fraser (2000) refers to as the identity model approach to recognition. Inherent in this approach is the idea that identity is constructed through a process of mutual recognition, where each person sees the other person as equal but separate or different. Becoming an individual involves recognising oneself and being recognised by others. Recognition is concerned with respect of human dignity and respect for a person's or group's culture or way of life. Recognition by others is considered to be essential to the development of a sense of self or a personal identity. This is what Taylor (1998) refers to as *ontological identity*.

The process of categorising people into groups is an important part of developing a sense of identity. People position themselves into categories or groups on the basis of differences such as gender, ethnicity and disability. People are also positioned into such categories by other members of society. Identity is related to a sense of belonging to such a category or group. Taylor refers to this as *categorical identity.* A person's sense of collective or social identity is drawn from their sense of being similar to other members of a group. For example, an ethnic group might be defined as a socially distinct community of people who share a common history and culture and often share a distinct language and religion (Stillitoe and White, 1992). People may draw their sense of ethnic identity from the common characteristics and similar experiences they share with members of an ethnic group. Collective identity also arises from a sense that the group to which one belongs or identifies is viewed by members of the group or by members of other groups as being different (Taylor, 1999; Gilson and Depoy, 2000). The categories with which people identify and into which they are positioned are often viewed as taken-for-granted categories. However, they are socially constructed.

Misrecognition is associated with social categories. Social categories usually reflect dominant social groupings (Fawcett, 2000). In addition, they tend to reflect the normative values held by society. Misrecognition occurs when the group to which one belongs is either devalued by the dominant culture, or is rendered invisible or subjected to disrespect. An example is simplistic and negative stereotyping of groups of people.

Misrecognition can be illustrated by looking at dominant discourses around disability in Western societies. On the one hand, there is a tendency for able-bodied people to be defined and perceived as 'normal'. On the other hand, there is a tendency for disability and the 'disabled' to be viewed and valued as 'abnormal'. This arises from a view of disability that is based on a biomedical framework. This model places an emphasis on individual impairment, loss and need for adjustment. In a similar way, Travellers are misrecognised in Ireland. Based on an examination of anti-Traveller racism in Irish society both historically and contemporarily, Fanning states that:

"It would be difficult to exaggerate the extent of racism and discrimination against the Travelling people in Irish society and the extent to which it remains justified within racialised discourses that construct the Travelling people as deviant and inferior." (2002: 5)

Misrecognition can lead to a person's identity becoming distorted or injured. Negative assumptions and stereotypes can be fed back to subordinate groups. Since a person's identity can be formed to some extent by how one is perceived and treated by others, the devaluing of a group can have the effect of enforcing a negative identity on people. For example, by rendering people with disabilities as 'abnormal' and inferior, disability is constructed as a devalued identity. People with disabilities acquire a negative disability arising out of the socialisation process and in the context of social relations. Oliver and Barnes (1998) point out that the majority of people with a congenital disability live in a family where there are no other disabled people. Since they do not usually have strong supportive role models within the family with which to identify, they grow up associating themselves with a conventional or negative disability identity. People with acquired disabilities find themselves ascribed with a conventional disability identity.

Addressing socio-cultural inequalities involves positively revaluing disrespected identities. One way of achieving this is to break the normative hold by dominant groups. This requires that members of devalued or subordinate groups resist the dominant culture's demeaning picture of the group and reject internalised negative identities. Resistance to negative constructions of identity is more likely to take place in a collective context. Thus, revaluing disrespected identities requires that subordinated groups have the opportunity to join collectively to interpret and produce positive identities of their own. Fanning describes how Traveller organisations:

"sought to contest dominant representations of Irish society as homogenous and to contest prevalent racialisations of Travellers as a 'deviant minority' by arguing that Travellers were an ethnic group." (2002: 159)

In contrast, the experience of disability as a negative identity is usually an individualised experience (Shakespeare, 1996), although the disability movement provides a collective context for a positive disability identity and for challenging a negative disability identity. In Irish society, people with

disabilities highlight that because they have typically been segregated from mainstream society, and often from each other, there are serious limitations to their sense of belonging and collective identity. Organisations of people with disabilities, such as the Forum of People with Disabilities, have come together to provide the collective context for the development of a positive disability identity. This is achieved in a number of ways: the adoption of a social model of disability, which focuses on 'disablism' and on how society physically and attitudinally disables people as an alternative to the medical model of disability; challenging negative views and stereotypes of disabled people; and developing a sense of shared cultural identity through disability arts.

### 2.3 The Notion of Multiple Identity

Approaches to recognition based on the notion of group identity are important for challenging claims of homogeneity in Irish society. They are also important for highlighting the effects of discriminations such as sexism, racism, or disablism against specific groups of people. The notion of *multiple identities* is also a useful concept. This is because it reflects the complexity of people's social identity. First, the notion of multiple identities highlights that there are differences between people *within* groups. For example, disabled people and black and minority ethnic people can often be presented as an undifferentiated, homogenous group of people. This may obscure the fact that people with disabilities themselves differ in terms of physical, sensory or intellectual impairments or that minority ethnic communities are culturally diverse. Second, people draw their sense of identity from a broad range of sources. We can use the example of a disabled refugee woman. Does she identify herself primarily as a woman? Or as a wife and mother? Does she identify herself as a disabled person? How important is her ethnic origin to her? Even at that we have not begun to explore how her identity is shaped by her religion, citizenship status, age and so on. The notion of multiple identities captures the richness and complexity of diversity among people and the complexity of people's lives. It does not impose a single group identity on people (Fraser, 2000).

As with single group identity, misrecognition is an issue with multiple identities. People can be misrecognised in society on the basis of more than one category. This could happen where negative stereotypes are attached to both categories within a multiple identity category. For example, as people with disabilities and as people from minority ethnic communities, minority ethnic people with disabilities may be rendered as 'multiple other' by the dominant group, by virtue of their deviation in more than one way from the norm (Vernon, 1998). Therefore, two aspects of a person's identity may be injured. From the point of view of the individual concerned, this could be experienced as double discrimination (Fawcett, 2000). Misrecognition can occur within groups. There may be commonalities within groups, but at the same time it cannot be assumed that commonalities exist because there will also be differences within groups.

It has been argued that the notion of single group identity can lead to the 'reification' of groups and single group identities. Fraser (2000) argues that emphasis on collective identity puts pressure on individual members to conform to a given group culture. Williams (1996) too questions the process of asserting a collective identity and asks whether the implications of asserting a common group identity are that other facets of a person's or group's identity are obscured or rendered invisible.

Williams also points out the significance of recognising commonalities and differences both within and across dominant and subordinate groups:

"... it is through the process of knowing, acknowledging and understanding the complex relations of power in which we are all caught and the differences that they create that we can, from time to time, reach the commonalities we share." (1996: 72)

Some concern has been expressed about using the concept of multiple identities. For example, it has been argued that people must be seen as 'holistic individuals' and concern has been expressed that the notion of multiple identities can lead to a process of fragmentation. This could mean that minority ethnic people with disabilities are simply seen as a product of what it is like to be disabled and what it is like to be from an minority ethnic community. For the purposes of exploring multiple

identities, it is important to have an understanding of identity that lies somewhere between single group identity, which glosses over pervasive difference, and the notion of multiple identity, which includes potentially infinite identities. This leads to the question of how people with a multiplicity of social categories of difference develop a coherent sense of self-identity. Taylor (1998) argues that a person can develop a unified sense of self even though they have more than one identity. Furthermore, Williams (1996) argues that individuals can hold multiple identities, but can temporarily freeze identities. She argues that to claim difference, which is defined as, "a situation where a shared collective experience/identity ... forms the basis for resistance against the positioning as subordinate" (1996: 70), it is necessary for people to temporarily freeze differences in their identities. The concept of multiple identities is, therefore, useful for exploring how people develop a sense of belonging to more than one group and become active citizens in articulating who they are and what are their individual and collective needs.

# SITUATION OF MINORITY ETHNIC PEOPLE WITH DISABILITIES

Irish society comprises diverse ethnic communities. Ireland's minority ethnic communities include Travellers, asylum seekers and emerging immigrant communities coming from a range of minority ethnic backgrounds. This chapter provides a profile of minority ethnic communities in Ireland and argues that people with disabilities are an invisible sub-group within minority ethnic communities in Ireland.

The chapter also examines key existing national statistics. These statistics could potentially yield important data for the purposes of identifying minority ethnic people with disabilities and for the purposes of equality monitoring with respect to this group. The absence of ethnic and disability identifiers from health data monitoring systems is also noted.

# 3.1 People with Disabilities Among Minority Ethnic Communities

Ireland is a multi-ethnic society. People from minority ethnic communities within Irish society do not form an homogenous group. They are made up of distinct groups of people (FAQS Research, 2001). Minority ethnic communities within Ireland include the Traveller community, an indigenous minority ethnic community with a distinct culture and a history of nomadism. A question relating to membership of the Irish Traveller community was included for the first time in the 2002 Census (Central Statistics Office, 2002a) and 23,681 Travellers representing 0.6% of the total population were enumerated. There are black and minority ethnic people among the rest of the population of Irish citizens. Among the non-national population living in Ireland a distinction is usually made between those who are from the European Economic Area (EEA - that is the EU member states as well as Norway, Liechtenstein and Iceland) and those who are non-EEA nationals. Most of Ireland's resident foreigners are EEA nationals who have the right to live and work in Ireland (Woods and Humphries, 2001). Within EEA countries, there will be citizens who come from black and minority ethnic communities. Some of them may come to live and work in Ireland. Together with black and minority ethnic Irish citizens, this group of black and minority ethnic people are often overlooked.

Ireland's population of non-EEA nationals includes students, migrant workers with their family members, as well as asylum seekers and refugees. There are also children from a minority ethnic background in Ireland who have come here through inter-country adoptions. They come from a range of minority ethnic backgrounds. There is no precise information on the ethnicity of these newly emerging communities. However, one indication of the ethnic diversity is the range of countries from

which non-EEA nationals originate. For example, asylum seekers and refugees come from over 100 different countries including Vietnam, Bosnia, Kosova, Romania, Nigeria, Algeria, Congo, Sudan, Somalia and Kurdistan. In 2001, the majority of asylum seekers originated in Nigeria and Romania followed by Moldova, Ukraine, Russia and Croatia. The main nationalities of work permit holders in that year were Latvians, Lithuanians and Poles (Woods and Humphries, 2001). Figures available show that in recent years there are approximately 10,000 asylum seekers applying for refugee status per annum, a figure that appears to be stabilising. Migrant workers outnumber asylum seekers and refugees in Ireland (Woods and Humphries, 2001). In 2000, the total number of non-EEA nationals with permission to remain in Ireland and not seeking asylum was approximately 47,000. At the end of 2001 the figure was 90,000 (Ingoldsby, 2002). This indicates a considerable increase since the end of 1999 when the number of legally resident non-EEA nationals stood at 19,000.

People with disabilities among minority ethnic communities are largely invisible in Irish society. Moreover, very little is known about the incidence of disability among minority ethnic communities in Ireland. This is the case both for Ireland's largest indigenous minority ethnic community, the Traveller community, and Ireland's newly emerging minority ethnic communities. The Traveller Health Strategy acknowledges that, "Travellers with disabilities may suffer from being an almost invisible sub-group within the Travelling Community" (Department of Health and Children, 2002: 86). The lack of data on Travellers with a disability was also acknowledged in the Traveller Health Strategy.

Similarly to the Traveller community, scant information is available on people with disabilities among asylum seekers and refugees in Ireland. Roberts (2000) has drawn attention to the fact that the presence of disabled people within the refugee and asylum seeking population in Britain is almost completely ignored and that refugees and asylum seekers are typically presented as young ablebodied men. Like Britain, there are difficulties in estimating the numbers of refugees living in Ireland, let alone knowing just how many refugees have impairments. Likewise, there is no information on what proportion of asylum seekers have impairments. Asylum seekers and refugees with a disability include those with a pre-existing disability who may have had their situation exacerbated by the conditions from which they were fleeing. Others may have acquired a disability arising out of war, conflict or torture. For many asylum seekers and refugees, the psychological trauma inflicted by conditions before and during flight, may lead to debilitating mental illness. SPIRASI – the Asylum Services Initiative – estimate that at least 10% of the asylum seeking population in Ireland have survived torture (SPIRASI, 2002).

There are also people with disabilities amongst migrant workers from non-EEA countries. Again, there is no data in Ireland with regard to migrant workers with disabilities. The UN points out that migrant workers often suffer from discrimination, poverty and social exclusion on arrival in the host country and the situation for disabled migrant workers is one of double discrimination. While it is likely that people with disabilities may be less inclined to migrate to Ireland for the purposes of taking up a job than able-bodied people, there may be a family member with a disability accompanying them. It should also be noted that the profile of minority ethnic people with disabilities is changing and will continue to change at the same time as the ethnic profile of Irish society evolves.

### 3.2 Minority Ethnic People with Disabilities in National Statistics

One of the problems in attempting to profile people with disabilities among minority ethnic groups in Ireland is the lack of reliable figures on the populations of ethnic groups. National data on disability among the working age population has only recently been produced. Nonetheless, the availability of data on the nine grounds covered by equality legislation is considered to be essential to the analysis and monitoring of progress towards greater equality in Irish society. Commitments to developing data on ethnicity and disability in Ireland exist.

Two key sources of equality data in Ireland are the Census of Population and the Quarterly National Household Survey (QNHS). The Census of Population and the QNHS are potential sources of data on disability and ethnicity, as discussed below. The National Intellectual Disability Database and National Physical and Sensory Disability Database (Health Research Board) are examined for ethnic

breakdowns. The need for generating data disaggregated by disability and ethnicity in health data monitoring is also noted.

#### **Census of Population**

The Census of Population is a comprehensive source of national data on the population. The Census is carried out once every five years, and is in essence a head count of the number of persons resident (or usually resident) in Ireland on a specific date. A range of additional information on individuals and households is gathered on the Census form. This allows a socio-economic representation of the population of Ireland to be built up at a particular point in time. The 2002 Census will be a key source of national data on disability, as it features two new detailed questions on disability as follows:

- 1. Do you have any of the following long-lasting conditions:
  - (a) Blindness, deafness or a severe vision or hearing impairment?
  - (b) A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying?
- 2. Because of a physical, mental or emotional condition lasting 6 months or more, do you have any difficulty in doing any of the following activities?

Answer (a) and (b) if aged 5 years or over.

- (a) Learning, remembering or concentrating?
- (b) Dressing, bathing or getting around inside the house?

Answer (c) and (d) if aged 15 years or over.

- (c) Going outside the home alone to shop or visit a doctor's surgery?
- (d) Working at a job or business?

Analysis of the Census of Population 2002 will thus generate new information on disability.

The 2002 Census did not include a general question on ethnicity, although it featured for the first time a question asking respondents whether or not they are a Traveller. There is widespread support for the inclusion of a question on ethnic group in the Census for the purposes of monitoring inequality, discrimination and poverty (see Barry, 2000; National Consultative Committee on Racism and Interculturalism, 2001; Quirke, 2002). The absence of a question on ethnicity in the 2002 Census means that it will not be possible to correlate disability with ethnicity and generate new data in terms of this multiple identity. However, it is important to note that analysing disability data (or indeed other socio-economic data) in terms of ethnicity is not clear-cut.

Work is currently progressing on developing a question on ethnicity in Ireland. The development of a question on ethnicity for inclusion in the Census is not straightforward. Rather, due to the range of different but closely related concepts or modes of identification (such as 'skin colour', nationality and place of birth) that can be and have been used to represent ethnic groups, analysing data in terms of ethnicity is a complex undertaking (Fenton, 1996). Account must also be taken of sensitive and ethical issues that arise in the course of collecting data on ethnicity (Conroy, 2002). Notwithstanding the difficulties, the development of appropriate categories of ethnicity must, according to Fanning (2003), become a core principle of Ireland's data collection strategy. Its availability would generate breakdowns by ethnic group in the Census data. Importantly, it could conceivably create the potential for the further analysis of disability data and identify minority ethnic people with disabilities, a group with overlapping experiences of discrimination.

#### **Quarterly National Household Survey (QHNS)**

The QNHS is a key source of data on labour market statistics. In November 2002 the Central Statistics Office (CSO) published for the first time data on disability in the labour force. This was in the form of an occasional report on disability (CSO, 2002b). The report is based on a set of questions on disability, which was included in the QNHS in the three months from March to May 2002. The questions on disability were asked to all persons aged between 15 and 64 years inclusively. The module on disability is an important source of data on disability. The data indicates that 271,000 or over 10% of all people aged 15 to 64 years have a longstanding health problem or disability.

The data shows that people of working age with a disability/health problem are less likely to be participating in the labour force. While 68% of all persons aged 15 to 64 years were in the labour force, the rate for those reporting a disability/health problem was just 43% compared with 71% among those that did not report any longstanding health problem. Furthermore, among people in the labour force, those who reported a disability or longstanding health problem had a higher rate for unemployment (6.5%) than the rest of the population (4.2%).

It is not possible to examine employment or unemployment levels of minority ethnic people with disabilities and to compare these with the overall rate of employment or unemployment among the total population of working age people with disabilities in Ireland. This is because data generated by the QNHS is not disaggregated by ethnic group. Furthermore, groups such as Travellers and asylum seekers as well as people with disabilities may be excluded from the QNHS as only private households are surveyed each quarter. A private household is defined in the QNHS as, 'any one persons or group of persons (not necessarily related) with common housekeeping arrangements, separately occupying all or part of a private, house, flat, apartment or other private habitation'. People living in institutions or Travellers living on the side of the road are therefore excluded.

### **Disability Databases and Health Monitoring Systems**

Since 1995, statistics are collected for administrative purposes in Ireland in the area of intellectual disability. From the information, the Health Research Board compiles the National Intellectual Disability Database (NIDD). Data breakdowns can be generated from the NIDD according to gender, age and degree of intellectual disability. However, information is not collected on ethnicity. With the establishment of the National Physical and Sensory Disability Database, a picture of people with a physical or sensory disability currently receiving and/or requiring specialised health and personal services will also be generated. Similarly to the NIDD, information on ethnicity will not be gathered.

Ethnic groups and people with disabilities are generally absent from health data monitoring systems in Ireland. For example, none of the forms used to record information for the following datasets gather information on ethnicity: National Mortality Dataset, Perinatal Reporting System, National Pyschiatric In-Patient Reporting System, Hospital In-Patient Enquiry, National Drug Treatment Reporting System. The absence of specific groups such as minority ethnic groups has been identified as a limitation of the health data monitoring systems. For instance, a study on inequalities in mortality in Ireland and Northern Ireland based on datasets in the period 1989-1998, concluded that the absence of data items such as ethnicity impose limitations on the ability to explore the relationship between inequalities and mortality. They recommended that data items on ethnicity and country of origin should be included in health data sets (Balanda and Wilde, 2001).

Community and voluntary sector groups have highlighted that eradicating inequalities in Ireland's health system must take account not only of socio-economic inequalities but also of inequalities on the grounds of ethnicity including membership of the Traveller Community and disability as well as the other six grounds named in Equal Status legislation (Community and Voluntary Pillar, 2001). The Programme for Prosperity and Fairness provided for data systems to be adapted to enable disaggregation of health access and outcomes across the National Anti Poverty Strategy's target groups, two of which are minority ethnic groups and people with disabilities. This data is to be monitored and reported on at national level (Government of Ireland, 2000).

Overall then, the invisibility of minority ethnic people with disabilities in Ireland is exacerbated by the lack of data making it difficult to statistically identify this multiple identity group and measure inequalities related to this group. Some progress has been made particularly with regard to the collection of data on disability. With commitments to developing questions on ethnicity, there is potential for the generation of data in relation to minority ethnic people with disabilities in the future. This will not be a straightforward exercise, given the particular problems associated with collection of data on ethnicity.

# **IDENTITY AND EXPERIENCE**

This chapter focuses on the identity and experiences of minority ethnic people with disabilities in Ireland. The chapter draws on interviews with nine minority ethnic people with disabilities living in Ireland. The chapter first examines the issue of identity and impairment and finds that minority ethnic people with disabilities differ in terms of how they understand, perceive and define themselves in terms of impairment. In addition experiences of discrimination on the basis of disability and dependency were key issues to emerge during the interviews. The chapter then goes on to explore the issue of identity and ethnicity. While participants had less to say about ethnic identity, issues of exclusion and racist abuse were raised by participants and are discussed below.

The chapter then presents some other key issues that emerge in relation to understanding identity for minority ethnic people with disabilities, including ambivalence in respect of identity, the importance of self-determination and claiming 'other' identities. Finally, the chapter explores 'associational identity', the extent to which the participants identify and are involved with groups and organisations representing minority rights as well as their experiences of such organisations.

### 4.1 Identity and Impairment

Participants in the study had been identified as 'minority ethnic people with disabilities' for the purposes of exploring people's multiple identities. There were variations among the participants with regard to how they defined themselves both in terms of impairment and ethnicity.

Participants in the study did not always identify with the label 'disabled person'. While some participants described themselves as disabled people, others did not 'self-identify' in this way. This is the case for many individuals with an impairment (Barnes and Mercer, 2003). In mainstream society, disability is conventionally viewed as a, "tragic problem occurring for isolated unfortunate individuals" (Oliver and Barnes, 1998: 3). This follows a medical model definition of disability. Through a process of socialisation, people in society can learn to view disability negatively and as abnormal. This is true for people with disabilities, as for non-disabled people. In the absence of a positive definition of disability, people with disabilities, including those from minority ethnic communities, may reject impairment in the construction of their identity (Shakespeare, 1996). This rejection or denial can take a variety of forms. The person may claim to be 'normal'. In addition, people with disabilities may try to minimise the importance of impairment in their lives and seek to overcome impairment by emphasising ability and activity. As one participant in the study remarked:

'I don't see myself as a person with a disability. It's only the other person who sees me as that. I don't like being idle or depending on anybody. I want to be myself, despite my impairment. Because I wasn't born with an impairment anyway, so I've been an able-bodied person before and I know how I've struggled through life. That's stayed with me. So, I don't see myself as a disabled person. I just see myself that I can do the work that others can do. In terms of, I have the IQ to work, not a physical job. There's not every job that I can do at the moment. Being able to get a job, I just want to be able to get a job and do like others can do. I can do that.'

A deaf identity which is, "constructed on the grounds of having a shared language and the experience of shared exclusion from a hearing world" (Ahmad, Darr and Jones, 2000: 67) follows a cultural definition of deafness. Deaf people who consider themselves as culturally deaf identify sign language as their first language. They can be distinguished from those deaf people who identify primarily with the hearing community (Taylor, 1999). A minority ethnic deaf person participating in the study had rejected a disability identity and following a cultural definition of deafness assumed a deaf identity. Furthermore, while he acknowledged his minority ethnic background it was with the deaf community and other deaf people that he most strongly identified:

'No, I don't see myself as disabled. The deaf community is important. It is the deaf community that I most strongly associate with.'

In their narratives about disability all participants emphasised what they were able to do. Participants spoke about ability and independence and stressed that they did as much as they could do:

'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. I have a home care, a home help.'

Following the social model definition of disability, which presents disability in terms of societal barriers leading to the exclusion of people with disabilities, many participants emphasised disabilist structures encountered in Irish society. Participants expressed the view that there was a general lack of awareness and understanding among people in Irish society of what it means to be disabled and the ongoing barriers preventing people with disabilities from participating fully in Irish society:

'The girls here don't understand me. They don't understand the balance problem I have. I'm trying to strengthen myself up a little bit. I'm getting there. Me being on crutches and that, it slows me down. When people are walking with me, they be walking too fast, I have to tell them to slow down. With the crutches, it's very hard for me to keep up with them.'

One participant illustrated the lack of awareness in Irish society about disability by referring to the lack of seating in many public spaces and services. This view could be understood as challenging the assumptions in Irish society about who is using public spaces and services. There was a view that Irish society should give greater recognition to the particular difficulties facing people with disabilities. One participant spoke about her experience of living in another country, where people with disabilities were given priority by the rest of the public as well as by services. For example, people with disabilities were allowed to proceed to the top of a queue. This, she said, was not her experience in Ireland. This participant also expressed surprise at not often seeing or meeting other people with disabilities. She wondered where the Irish people with disabilities were. The invisibility of people with disabilities in Irish society is likely to be a reflection of the segregation of people with disabilities in Ireland.

In addition to societal disabling barriers, the subjective experience of living with impairment was a central part of everyday life for many participants. Some participants spoke about their experiences of living with problems of impairment on a day-to-day basis. They spoke about the degenerative or progressive nature of their condition, of the pain they suffered or the mobility problems associated with their impairment and how this affected their lives. What they were able to do and their experience of disability was not only determined by disabling barriers in society, but also by their

physical impairment or health problem. This could often make daily life very difficult:

'It is getting worse and worse. It affects the whole body. Kidney, heart, eyes. It's just progressive, advancing. It is very difficult to stop it without proper treatment. 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.'

These participants also expressed feelings of fear and anxiety. In some cases, disability was also associated with loneliness, isolation and rejection:

'With the disability that I have, I keep falling an awful lot. I feel kind of scared and frightened. I feel kind of alone. Nobody is there for me. That's how I feel.'

As people with impairments, a key issue for many participants was around overcoming dependency and gaining more autonomy and control over their lives and becoming independent. Getting an education, learning to use computers, being able to drive and having access to a car and independent living were all ways of gaining more control and autonomy. One participant who was born deaf insisted that, 'I want to go to school' just like his brothers and sister. His parents assumed that a deaf person could not be educated. Their attitude was that, 'He's deaf, just leave him there'. His persistence eventually paid off. His parents found out about schools for the deaf and at eleven he began his education and completed first, second and third level education. Another participant explained:

'I'm planning on doing an independent living course in Dublin. I tried to get in straight away but you have to wait about two and a half years. It's living for six months in a place and you kind of see if you can go shopping and d'you know this sort of thing, to be independent in your own home, that kind of thing. To go shopping and whatever you want. You can also get a personal assistant. It lasts about six to twelve months. I'd have to move to Dublin. They didn't want doing that either. They think you should stay with your own mother and father, which I don't want to. 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.'

### 4.2 Identity and Ethnicity

The participants in the study come from a diversity of minority ethnic backgrounds. Some are Irishborn. Others arrived in Ireland as asylum seekers or refugees. When defining themselves in terms of ethnic identity, some participants used country of origin such as Nigeria or continent of origin such as Africa as descriptors. Apart from members of the Traveller community, participants rarely referred to specific ethnic groups. Some participants used a combination of descriptions such as place of birth, family background and ethnic group, for example, 'I am an Irish Travelling person. I was born in Ireland. Both my parents are Irish Travelling people.'

#### **Exclusion from Social Networks**

As minority ethnic people, many participants identified with the issue of social exclusion. Social exclusion can be defined in terms of, "cumulative marginalisation from production (employment), from consumption (income poverty), from social networks (community, family and neighbours), from decision-making and from an adequate quality of life" (Government of Ireland, 1996: 17). This definition includes a focus on social networks, which was a form of exclusion experienced by some of the participants in the study.

As minority ethnic people, some participants found themselves excluded because their culture and language differed from that practised in mainstream Irish society. Common culture and language shared by minority ethnic groups are widely recognised features of ethnic identity. Some participants found that these differences served to segregate, exclude and isolate them. Not speaking English was a major barrier to participating in Irish society. This situation was compounded for older people who

experienced difficulties learning new languages. As an older participant explained:

'The biggest problem if you want to socialise in Dublin with Irish people is language. That means that you are a little bit excluded. For elderly people, it is very difficult for them to learn English.'

It would appear that maintaining links with people from the same minority ethnic background is particularly important for providing asylum seekers, refugees and immigrants with a sense of security and belonging. One participant who had arrived in Ireland as a refugee explained the importance of this. He had arrived from a conflict situation and was experiencing insecurity and displacement. Being among people from his own ethnic background, being able to communicate with them and being able to give and receive support gave him a sense of belonging and a sense of security. Maintaining links with people from the same minority ethnic community continued to be important. However, increasingly, it was also seen as a barrier to integration into Irish society. The lack of good English language skills presented a major barrier to integration. The participant also felt excluded from social networks. For him, ethnic identity came to be associated with issues of exclusion.

#### **Racist Abuse**

In addition to the disablist barriers in Irish society that structured the experience of many participants as a result of having an impairment, many participants also identified with issues of racism, which they faced as minority ethnic people. Racism is a specific form of discrimination. It is based on the false belief that some people are inherently superior to others because of different skin colour, nationality, ethnic or national origins. It can present itself in various forms of racist behaviour, racist harassment or racist discrimination.

Some participants in the study reported experiences of direct or overt racist abuse. This is not surprising given that black and minority ethnic communities living in Ireland experience a high level of racist abuse (FAQS Research, 2001). The experience of minority ethnic people with disabilities interviewed mirrored those of people from black and minority ethnic communities in wider society. For example, skin colour or dress of individuals from black and minority ethnic communities often serves to single black and minority ethnic people out as targets for racist abuse. This was often the basis for racist abuse of minority ethnic people with disabilities participating in this study. One participant put it in the following terms:

'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.'

One woman had on occasion been singled out because of her skin colour and dress. She had been called names and pushed in the neighbourhood in which she lived. She and her family were advised by the police that the best solution would be to move house, which they did. Since then, she or her family have not, at the time of interview, experienced racist abuse. Another participant reported that he had regularly encountered discrimination in trying to access services and facilities. He was refused the use of the service on the basis that there were 'enough Irish'. Experiences of racist abuse mainly occurred on the street, in public areas and mainly took place in disadvantaged urban areas. Experiences of racist abuse were incidental occurrences. Not all of the participants in the study had experienced direct racist abuse.

### 4.3 Identity Issues

#### **Ambivalent Identities**

Within their own minority ethnic communities, minority ethnic people with disabilities are faced with social barriers such as the inability to attain accepted roles (Stuart, 1998). This may lead to a sense of ambivalence about one's identity. Some participants in the study expressed ambivalence towards their ethnic identity. On the one hand, ethnic identity was important to them. On the other hand, they

described how they were prescribed roles as disabled men or disabled women based on cultural perceptions and traditions of the ethnic group. This was particularly the case for those born with a disability and is not unique to minority ethnic communities. Participants disliked when such roles were prescribed and the low expectations that people, their parents and other members of their community had of them as disabled people. They felt that this undermined them as people:

'Being [from a minority ethnic community]. 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 ... Being a woman was a reason for not getting an education. Disability is just 'forget about education.'

#### Self-determination of Identity

The principle of self-determination refers to the right of an individual to determine who she or he is in terms of their identity. There was a strong desire among some participants to define who they were both in terms of impairment and ethnicity. This suggests that self-determination is important to people. Many participants did not want to be classified by other people. This could mean confronting other people's classification and presenting one's own description of who one is:

'Mostly where I go they don't recognise me as a Traveller.You know the way you see some people and you know straight away that they're Travellers.That seems to be hidden in me, because when I go out there, they think I'm a settled person.Whatever I say or do.Whatever I give off about me.They don't know I am unless I tell them. I often did and then they are surprised.'

#### **Claiming 'Other' Identities**

One of the issues for people with multiple identities that emerged in the course of the interviews was around the difficulties and tensions that arose for people in claiming identities. Difficulties and tensions arose where participants were claiming an identity such as a religious identity or a gay identity that was viewed as 'other' or 'inferior' by a group to which one has a sense of belonging. To the group, the two identities were considered to be incompatible. Claiming an 'other' identity could result in discrimination and abuse. It is argued that the internalisation of discrimination can produce a negative identity. Claiming all of one's identities appeared to be very important to participants. They spoke about being true to oneself. It would seem that claiming identities is important to the integrity of self and for developing a positive sense of self:

'Religion is very, very important to me as a person. Of course, I'd love to be in contact with my own people, but I don't see anything that I would benefit from that. I'd rather be on my own, because of my belief, because the way I live my life would not be the way they live theirs. It might not be compatible. My best bet is to be myself. So, I would not get involved. Because of my religious belief, because of that, I stay from getting closer to them. The ones I want to, I get to know people individually, irrespective of where they come from.'

Matters of identity also influenced key decisions and choices in life. Claiming one's identity, even if it conflicted with the group's views, was about making the right choices. It also brought with it responsibilities both in relation to the self and to other people.

'The whole truth was that I actually was a gay man and in [my] community that was a nono. There were expectations that I was to get married and that. I suppose I was a levelheaded and sensible chap at the time although I didn't think I was. I didn't put myself into situations that I would hurt myself or hurt somebody else and live a lie. You kind of had an understanding of what was right or wrong for yourself. I know it would have been wrong to engage in a marriage. It would have been wrong for me, for the woman and for any children. I suppose you have to take a sense of ownership of who you are and what your are and you have to take a sense of ... what comes along with ownership is a sense of pride and what you're worth and you want more for yourself.'

# 4.4 Associational Identity

A distinction can be made between ethnic identity implicit in *distinctive cultural, religious and linguistic practices* and *associational identity* (Modood, 1998). *Associational identity* takes the form of pride in one's ethnic origins, identification with certain group labels and, sometimes, political assertiveness. Modood (1997) has found that the most widely shared sense of a minority ethnic community is only partly related to cultural and behavioural practices, and that associational or community identity, where one shares a sense of belonging to a group, is the most common expression of ethnicity. Associational identity can take a variety of forms. For example, one woman participating in the study referred to her participation in an African Women's Choir.

### **Minority Ethnic Community Groups**

Ethnic identity can become politicised for some people and can become a primary focus of their politics. Modood argues that:

"There is, in Britain an ethnic assertiveness, arising out of feelings of not being respected or of lacking access to public space, consisting of counterposing 'positive' images against tradition or dominant stereotypes. It is a politics of projecting identities in order to challenge existing power relations: of seeking not just toleration for ethnic difference but also public acknowledgement, resources and representation." (1998: 34)

Organisations in the UK promoting the rights of minority ethnic groups have been accused of ignoring disabled people. Stuart (1998) argues that black disabled people cannot fully associate with the interpretation of their situation, which is provided by black and minority ethnic communities fighting against racism. Yet, Vernon (1998) argues that 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 was the experience of at least one participant in the study.

Another participant chose not to get involved with a minority ethnic community group so as to avoid discrimination on the basis of other identities that he held. He was, however, able to engage with the organisation as a service user and to avail of resources of the organisation:

'I don't really want to be involved the way others are. Certainly I do go there when I have something to sort out. I feel I can go to get the solution, the answer to my problems there. If I need information, I sometimes go there. If I feel like I can sort something out on my own, I do it myself.'

Some participants were involved as employees in community projects working exclusively with minority ethnic communities. Such projects offered the participants employment. In addition, they acted as a major source of support and provided assistance. By providing services such as disability rights information and interpreting facilities, these organisations were a very important vehicle for overcoming barriers.

### **Disability Rights Based Organisations**

People with disabilities have come together to form their own organisations. The Forum of People with Disabilities is an example of one such organisation in Ireland. According to Oliver and Barnes (1998), organisations of people with disabilities have afforded disabled people the opportunity to discuss and re-evaluate their individual and collective experiences. This in turn has contributed to a positive perception of self and disability identity. However, minority ethnic people with disabilities may face marginalisation within disability movements and organisations. In the UK, organisations of

disabled people have been accused of ignoring the needs and rights of disabled people from minority ethnic groups (French, 1994). These organisations have only recently begun to address issues of difference and diversity including in relation to ethnicity (Fawcett, 2000).

At the time of the interview none of the participants in this study were involved with disability rights organisations. Many of the participants were unaware of the existence of 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.'

As in the UK, disability rights based organisations in Ireland are beginning to acknowledge and address issues of difference and diversity, for example, the Forum of People with Disabilities in 2002 states in its submission to the Health Working Group of the National Anti-Poverty Strategy that, 'It is also clear that Disabled Children, Women and Older people and those of different Ethnic or racial origin and Sexual Orientation encounter multiple layers of exclusion and poverty.'

Some, but not all, participants were in contact with disability organisations or support groups. Engagement with these organisations was as service users. Participants in this study stressed the importance of the support given to them by such organisations. For some, these organisations were also an important social outlet:

'There's one [a support group] just down that road. I go to that. I find that very helpful. They give me loads of support and all that. They don't call me names or nothing. They don't see me as a different girl. They see me as [name]. They don't see me as a coloured girl.'

Participants from new minority ethnic communities were less likely to be in contact with disability organisations and support groups. Recent research has been carried out on the involvement of new minority ethnic communities in community and voluntary sector organisations in Ireland (Faughnan and O'Donovan, 2002). The research found that voluntary and community organisations are, for the most part, at a relatively early stage of working with new ethnic minority communities. The study concluded that:

"There is an acute awareness among some organisations of the need to embrace diversity and to develop their own inter-cultural competence. Addressing communication difficulties, developing culturally sensitive practices, expanding their understanding and making information accessible are all identified as major issues and challenges to the sector." (2002: 14)

Faughnan and O'Donovan noted that while there was an imperative for voluntary and community organisations to expand services, resources and initiatives and actively and strategically promote the movement towards interculturalism among some organisations, this could not be said for all organisations:

"They [other organisations] seem to be hesitant, unsure about how to proceed and have not yet found the leadership, the incentive or the mechanisms to begin to strategically address an area they know is important in the development of Irish society." (2002: 14)

Many of the participants from minority ethnic communities with disabilities expressed a strong desire to meet with other people with disabilities and be in contact with and involved in disability organisations. Some considered that it would help them as a person with disabilities to overcome a negative sense of identity:

'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 then feel completely isolated. Generally for people with disabilities to share their experience and overcome the isolation.'

Faughnan and O'Donovan's research found that refugees and asylum seekers were most likely to be involved in community and voluntary organisations as recipients of a service or as users of a resource. They found that organisations involving refugees and asylum seekers as committee members, employees or volunteers were most likely to be organisations working exclusively with refugees and asylum seekers.

Participants in this research did not just want to be service users of disability organisations. Some wanted to be involved at a different level. For some, being involved in organisations of people with disabilities would give them the opportunity to make a contribution:

'I would like to be involved, if possible, to help as well, especially for other people from other nationalities, because I feel I would understand how they feel.'

#### Identity with Deaf Community

Earlier it was mentioned that one participant had a deaf identity and identified most strongly with the deaf community. The participant was involved with an organisation of deaf people. 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 encouraging the deaf community and clubs in Ireland to recognise diversity within the deaf population. He suggested a number of ways of overcoming racism within the deaf community. These included forming a group against racism in the Deaf Club in which he was involved and organising a conference to address issues of diversity and racism within the deaf community. He reported that the organisation was receptive to these suggestions and recognised the importance of addressing these issues.

#### Associations of Minority Ethnic People with Disabilities

In the UK, various groups of disabled people from minority ethnic communities have been formed from the late 1980s onwards, which were established to lobby for change in relation to their own distinctive situation. Examples include the Association of Blind Asians, the Asian Disabled People's Alliance and the Black and Ethnic Disabled People's Group. According to Drake (1999), emerging groups of disabled people from minority ethnic communities serve to provide a voice for this group of people. Drake also sees their formation as an acknowledgement of their exclusion from minority ethnic communities. These include limited funding and resources as well as exerting limited influence. Despite these difficulties in Britain such groups were found to have made a very real contribution to the positive identity of minority ethnic people with disabilities. Their impact on mainstream voluntary organisations is less clear.

As yet, there are no examples of groups of disabled people from minority ethnic communities coming together in Ireland. However, some participants in the study expressed a desire to meet and share their experiences with other minority ethnic disabled people.

# ACCESSING HEALTH SERVICES AND PARTICIPATING IN EMPLOYMENT

This chapter explores the experiences of minority ethnic people with disabilities in accessing public services in the health sector and their experiences of participating in employment in Ireland. The health sector and the area of employment were chosen so that the focus of the study would be consistent with that of the other five studies in the Joint Equality and Human Rights Forum research project. The chapter draws on interviews with the nine study participants.

# 5.1 Experiences of Accessing Health Services

This section of the chapter discusses the experiences of the participants in accessing health services in Ireland. Some participants remarked that they currently had little need to access health services and made few comments.

There are disability issues to be considered when exploring the experiences of minority ethnic people with disabilities in accessing health services. These range from attitudes to people with disabilities held by health care staff to the lack of access to buildings for people with physical impairments or poor transport facilities in order for people with disabilities to get to health services. As we saw earlier, some participants spoke in the interviews about the disabling barriers that exist in Irish society. However, participants had less to say about experiences of disabling barriers within health services. The difficulties experienced by a deaf participant in communicating with health care staff is illustrative of the disabling barriers that can face minority ethnic people with disabilities in accessing health services. Some participants as well as health care staff raised concerns about difficulties encountered by minority ethnic people with disabilities in seeking to adapt private rented accommodation to meet their needs. Others experienced the lack of urgency of health care staff in responding to their needs as disabling.

The most important barriers raised by participants which prevented them from accessing health services included lack of knowledge about services, poor access to information as well as language and communication barriers. When the participants talked about their experiences of health services, they did not often mention racism. The issue of discrimination against Travellers with disabilities in health services was raised by one participant as well as by health service staff, and their experiences and views are discussed below under the heading of institutional racism. Institutional racism refers to a situation where things are done in a way that assumes that all clients are from the same cultural, ethnic and linguistic background as the rest of the white majority population (Baxter, 1995).

#### **Knowledge and Information**

Lack of knowledge about services can be a barrier preventing minority ethnic people with disabilities from accessing services. Information is vital for people to access health and disability services. Disability organisations were an important source of information for some participants:

'The [disability organisation] has been very supportive. They're there whenever you want. They've given me all the information that I need. Any information you need. That's the place to go.'

However, most participants indicated that they had limited knowledge and information about the full range of services available to them as people with disabilities. There was also a general lack of knowledge about where to go to get information about services for people with disabilities. For example, many of the participants were unaware of the existence of Citizens' Information Centres.

The problems facing asylum seekers and refugees in relation to accessing information on rights, entitlements and services has been highlighted in other studies (Kennedy and Murphy-Lawless, 2002). Furthermore, awareness of the barriers facing people with disabilities in accessing information have been found to be low across a range of information giving services at local level (Ralaheen Ltd, 1999). The provision of services to minority ethnic people with disabilities entails providing information in ways that takes account of their needs as minority ethnic people and as people with disabilities. Assumptions can be made about the way that people use information. A Chinese community health project worker in the UK made the following point:

"Leaflets don't help. They are a waste of time. Some people don't have literacy skills in their own language. They also don't know the jargon used within the information available. It is meaningless. We are bombarded with paper but information needs to be released in different forms, not just because of language and literacy, but because people might also be disabled in different ways." (cited in Dunning, 1998: 11)

One participant in the study was aware that a local centre for people with disabilities that she frequented had *'loads and loads of leaflets'*. However, she said she didn't use these and that she preferred when information was communicated to her verbally.

#### Language and Communication

Language barriers to accessing health services were raised in the interviews by those who did not speak English as a first language. Participants with poor English language skills identified language as a barrier to information. One participant explained that even if he did know where to go to get information, language was a barrier. Participants also pointed out that many of the leaflets and booklets setting out rights, entitlements and services for people with disabilities were only available in English and were not of much use to them. An inadequate response by service providers to difficulties experienced by people with disabilities from minority ethnic communities who do not speak English can result in a lack of communication.

For deaf people, communication difficulties can be particularly pronounced. One deaf participant commented on the lack of sign language interpreters in most state services and agencies. He explained that he did not have access to an interpreter when he used hospital services. He had to bring his own interpreter, usually a friend, with him to facilitate communication. However, an interpreter was not always available to accompany him. He explained that *'I can't talk'* and without an interpreter the only way to communicate with staff in state services and agencies was by writing notes on pieces of paper to communicate what he had to say. Often he was expected to express himself in writing as opposed to through sign language, which was a very difficult and unsatisfactory way of communicating and expressing himself. Even when Irish sign language interpreters are available, deaf minority ethnic people continue to face communication barriers. Sign languages in different countries differ completely from each other, just as spoken languages differ from one country to another. For a deaf person who has learnt a different sign language, communicating

through Irish sign language is like speaking a foreign language.

Language is not the only barrier to communication. Black and minority ethnic groups may have different communication styles and cultural differences in communication styles needs to be respected, such as differences in non-verbal modes of communication. One participant explained that deaf people in his country of origin use sign language to communicate with each other and the hearing community. They rarely used 'oralism' as a form of communication. In contrast, many Irish deaf people have been taught to lip read and communicated orally with the hearing community and other deaf people. He felt that there was a level of expectation in Irish society of deaf people to communicate orally with the hearing community. This was not something that he had encountered before.

Assumptions among service providers about user knowledge and understanding of how services work or are organised can also act as a barrier to accessing services (Ralaheen Ltd., 1999). Comprehension is an important element of communication. Information may be transmitted in a message, but successful communication is completed only if the receiver understands the piece of information in the message. Ensuring that the information provided is accurate and that the information is understood by the receiver are vital elements in information provision to people from minority ethnic communities, especially if they have limited knowledge and understanding of how entitlements and services work or are organised. This is illustrated by the experience of one participant. The participant related an incident when, as an asylum seeker seeking refugee status, she received information that led her to believe that she would be entitled to services once she had been granted refugee status. However, such an entitlement did not exist. She was perplexed and disappointed when she was granted refugee status to find this out.

Lack of time to communicate effectively was identified by voluntary and community organisations working with asylum seekers and refugees as a concern for minority ethnic people with disabilities. They argued that more time needed to be spent with minority ethnic people with disabilities to introduce them to new health care settings, explaining procedures and alleviating stress and anxiety. This raises the need for more flexibility in health care services.

#### **Institutional Racism**

The institutional barriers preventing Travellers from accessing health and other services have been documented elsewhere (Fanning, 2002). Travellers with disabilities also face such discrimination. For example, in common with the rest of the Traveller community, Travellers with disabilities can be discriminated against because they do not lead a settled way of life, a factor which is not normally accommodated by Irish health services. One participant in the study described how health services in England had readily accommodated the Travellers' nomadic lifestyle and felt that similar practices could be adopted in Ireland:

'We had a very good arrangement with the hospitals. They accommodated that I would just turn up, because we never had a permanent address. They would give you like a ball park. Say 'Now in eight months time we need to see you back again'. And so we knew the secretary very well. And we knew the consultant who became very good friends with my family.'

The issue of institutional racism against Travellers with disabilities was raised by a public health nurse working with Travellers, who considered that Travellers faced major discrimination in accessing health services in Ireland and that anti-Traveller racism was also directed at Traveller families with children with disabilities. In her view, Traveller families encountered particular difficulties when trying to access services for their children. She cited the example of a Traveller family with a young child who had profound intellectual and physical disabilities since birth. She explained that all parents experienced difficulties in accessing long-term residential care for children with disabilities. The experience among parents was that their children were only placed in residential care after a lengthy process of lobbying. This involved writing and putting their case repeatedly to a range of health care professionals including consultants, GPs and other hospital staff as well as local TDs. This had become the

established and accepted practice among parents and within the health services.

However, as this became the dominant practice, it led to inferior outcomes for Traveller parents and their children with disabilities. It can be considered to be a form of institutional racism. The practice assumes literacy among all parents. It assumes that there was one cultural practice that all parents adopted. It ignores the fact that some parents may have faced discrimination in the past in their dealings with the medical profession and may therefore be reluctant to put their case forward for fear of further discrimination. The situation for Traveller parents was further compounded when they expressed anger and frustration at their situation. Travellers' frustration was interpreted as aggressive behaviour and became 'unpopular' among staff working in health services.

Stereotyping is another way in which racism is perpetuated in health services and can result in people not being able to access services. A public health nurse working with Travellers gave an example of this during the course of the research. She explained that the common practice in health services was for Traveller parents to be refused access to respite care services for Traveller children with disabilities. This was because it was generally believed that Travellers would not collect their children once the period of respite was over. This was based on the assumption that *'that is what Travellers do'*.

Community and voluntary organisations working with asylum seekers and refugees explained that some minority ethnic people with disabilities may be reluctant to approach state agencies or institutions due to fear, suspicion or distrust due to past experiences in their country of origin. Furthermore, asylum seekers and refugees with disabilities may be uncertain about their status and may be unwilling to seek assistance. Their reluctance to engage with state services was often viewed by service providers with suspicion. This feeds stereotyping.

Some health services workers commented that they had little awareness and understanding of other cultures and that training in this area would be welcomed. One worker had raised this issue within her own organisation but the organisation did not know where to find out more about anti-racism training. Another health service worker welcomed the Traveller awareness programme that was being introduced in health services but expressed concern about the potential of the programme given the deep-seated prejudice and anti-Traveller racism that she encountered among some staff.

#### **Accommodation Issues**

Accommodation issues were raised during the course of the study by participants as well as by service providers. One of the main issues highlighted was the barriers preventing people with disabilities living in private rented accommodation from accessing aids and equipment. Participants and health service providers raised this issue. For example, one participant explained that a recommendation had been made by a health worker for aids and equipment to be installed to assist her to climb the stairs and use the bathroom. Without the aids, she frequently had accidents inside her home. As a result of these accidents, her condition was exacerbated. However, she was later informed that the health board could not fit the necessary aids and equipment for her because she was living in private rented accommodation. A service provider cited the example of an asylum seeker woman. She was living in private rented accommodation to lift her up and down the stairs. Again, it was recommended that aids and equipment should be installed and again this did not happen because she was living in private rented accommodation. People with disabilities living in private rented accommodation was built and again this did not happen because she was living in private rented accommodation. People with disabilities living in private rented accommodation.

#### **Urgency of Response**

Some participants, particularly those with a degenerative condition or chronic illness referred to the degree of urgency with which some health professionals responded to requests. The issues raised surrounded requests for information, a diagnosis or treatment, physiotherapy and aids. Some participants felt that their requests were not treated with urgency and waiting for prolonged periods for a response left them feeling anxious and concerned:

'They left me in the wheelchair the whole time. I used the frame and only recently I went to this [wheelchair]. They don't seem to be concerned. I get very concerned. And I know there is things that they can do with my legs. Also, an exercise bike to keep the legs moving. The last day I was in there, she said that she was going to get in contact with the society and I haven't heard anything since. I need physiotherapy and I have had some only once or twice. They seem to put me down about it all the time. And I don't like it.'

One participant who was disabled due to a rare and chronic illness experienced barriers in trying to get a diagnosis of his illness upon which he depended in order to get treatment for his condition. His experience highlighted the importance of information capacity. He explained that once he acquired the information he needed he was able to use the information to gain access to health services:

'My diagnosis was there when I arrived [as a refugee] seven years ago. I didn't know where to go at that time. All doors were closed, even the hospitals, regarding my illness. They were trying to say that because of interpreters that they couldn't establish a proper diagnosis. That was just an excuse. It is just the system. I can't blame anybody. It is just generally a problem with the health system in Ireland. They never tried to do any research. Accidentally, one friend found information over the Internet about recent cases and how the illness was treated in other countries. We pressurised the health board. Finally, they started working with me to help me get treatment. That was about one year ago.'

# 5.2 Experiences of Employment

"It would be difficult to overestimate the importance which is attached to employment in Irish society today. The term 'employment' relates to far more than how people occupy their time and earn their living: it harks back to the very core of personal identity and the question of how we measure an individual's self worth." (Tubridy, 1996: 66)

This section explores the experiences of minority ethnic people with disabilities in relation to their participation in employment. As noted earlier, recent data shows that people of working age with a disability/health problem are less likely to be participating in the labour force. The attachment of participants to the labour market varied greatly, ranging from non-participation to marginal attachment to full participation in the labour market. There was also a marked variation in the type of work in which they were engaged. Of the participants in this study, two were employed in the open labour market. Two participants were engaged in community employment schemes and one participated in sheltered employment. One unemployed participant had undertaken a FÁS training course and at the time of interview actively seeking employment. Two participants had never participated in the labour market and one participant was an asylum seeker without the right to work. Their experiences are documented below.

#### Non-Participation in the Labour Market

Two participants in the study had never participated in the labour market and were not actively seeking employment at the time of interview. Both were women. One of the women had significant physical impairments arising from a degenerative condition and was unable to participate in employment. The other woman expressed a desire to get a job, but a range of physical and attitudinal barriers had prevented her from participating in the labour market. She explained her non-participation in the labour market in terms of attitudes held towards her as a disabled woman within a minority ethnic community. Traditionally, there has been a general belief within the community as well as within the wider Irish society that people with significant disabilities should be exempt from work. This was her experience. Furthermore, she had no formal educational qualifications and this she pointed out would prevent her from obtaining employment. She went on to explain that she did not receive much education because of expectations within the community that girls would get married and therefore didn't need an education. Furthermore, expectations of disabled people were low and education was considered to be irrelevant:

'It wasn't expected of me to go to work. It is something I would like to do in the future. You need your leaving Cert.'

She also pointed out that a lack of physical access to buildings for educational or training purposes had hindered her chances of accessing second chance education and training:

'I was thinking about doing a FÁS 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.'

Location presented another problem. The woman lived in a town without easy access to third level education. She had not up to now had the opportunity to live independently and this was a further barrier as she was dependent on her family and thus she was prevented from moving away to access third level education:

'Well, there's not really anything in [the town]. Like, they're all in Dublin like, the colleges and stuff like that. I'd love to go to college or university. But there's nothing available in [the town]. I'd love to do it.'

#### **Actively Seeking Employment**

One participant who had been granted refugee status defined himself as unemployed. However, he emphasised very strongly his desire to secure employment. For him, employment was seen as an important means of contesting disability in terms of dependency and counteracting a negative disability identity:

'In fact, I'm very desperate to get a job because I don't like being idle or depending on anybody.'

The participant who was very active in his search for work had made a large number of written applications. These applications were directed at career positions for which he considered himself to be qualified. Despite his active search for employment, he was unsuccessful and had received very few replies and had not been called for any interviews:

'All the CVs I've sent out, they've always replied that either I am too overqualified for the job that I am seeking or maybe I'm not suitable for the job. I haven't got to the stage of being interviewed. I haven't had any interviews yet.'

He attributed his lack of success to a downturn in Ireland's economy:

'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. If the situation was still like when I came here, when they were looking for people to work here, looking for people to come to Ireland to work you know.'

He did not attribute his lack of success in securing an interview to racist discrimination. However, he was aware that employers could negatively vet his application once they saw his name or where he received his education:

'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. Unless, they can feel that they cannot get somebody else, I think an amount of risk is in the country. Maybe time will come that it will be glaringly obvious'.

Another participant in this study explained that he carefully excluded any information such as

addresses from his CV that would identify him as a Traveller to a potential employer and leave him open to discrimination on that basis. As well as racist discrimination, people from minority ethnic communities with disabilities can face disablism. One participant felt that, once a potential employer became of aware of his disability, it would be an obstacle to securing employment:

'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. I just want to be myself. Maybe when I go to the interview because of ... Unless I just want to prove what I am to them, you know.'

A study of people with significant physical disabilities in Ireland found that many of the participants had gone through difficulties before eventually finding employers who were willing to employ them (Tubridy, 1996).

### **Engagement on Community Employment Schemes**

Two participants were engaged on a Community Employment (CE) scheme in a project responding to the needs of refugees. Community Employment provides unemployed people and other groups such as people with disabilities a chance to engage in work within their own communities on a temporary basis. Both participants stressed the importance of employment on the CE scheme to them and expressed concern that the CE scheme was due to come to an end. Neither felt that they had any hope of moving on to full-time paid employment. One participant had severe difficulties due to an ongoing illness and was limited in what jobs he could do. The project was able to accommodate his situation and he was unsure if other employers would be able or prepared to accommodate him in the same way. As he was waiting for treatment for his illness there was an amount of uncertainty about his future. He felt his chances of gaining a job were further limited due to his age and because he had poor English language skills. The other participant was a professional and experienced artist. He had encountered many barriers in trying to get established and work as an artist in Ireland. These included language barriers, lack of information, lack of finance, lack of artist space, discrimination in trying to access services and facilities for artists, lack of contact with other artists and exclusion from social networks to which Irish people had access. These and other barriers have been encountered by other minority ethnic artists in Ireland (Healy, 2002). Another participant in this study also identified lack of support for work search activities as a barrier to employment.

#### **Sheltered Employment**

One participant was engaged in sheltered employment. She spoke about how much she enjoyed work. Her narrative suggests that work is very important to her because it allowed her to be in contact and socialise with other people of her own age and to make friends:

'We do packing for companies and all. I like going out to work. I like that group. It's very relaxing. They have a bit of a laugh. The people that I'm working with, they're happy. They see me for who I am. I like the job. It's very nice. I wouldn't leave it for nobody. I like it very much.'

#### **Employment in the Paid Labour Market**

Two participants were engaged in paid employment, one in full-time and one in part-time employment. One of the participants worked as a book-keeper and reported that her employer was very supportive of her and had offered to pay for English language classes. As a person with disabilities, the biggest difficulty she faced in the workplace was getting to and from work on public transport, which she found was not very accommodating of people with mobility problems. One of these participants worked as a health professional in the health sector and reported having experienced racism in work in Ireland. This took a number of forms. He encountered negative stereotypes on an ongoing basis. He also encountered direct discrimination. In one job, he was 'let go' after a probationary period. The basis for not keeping him on was that he had revealed his ethnic identity to other members of staff and his employers decided that because of his ethnic background he would not fit in. As a result of his past experiences, he has taken a decision to suppress his ethnic identity in the workplace.
## Asylum Seekers Without the Right to Work

One of the participants in this study was an asylum seeker without the right to work. Currently, some groups of asylum seekers are not entitled to take up employment. Asylum seekers who made their application for asylum in Ireland after the 27 July 1999 are not permitted to work. As an asylum seeker he was excluded from availing of educational or employment opportunities.

A number of themes emerged in the interviews with minority ethnic people with disabilities. They are as follows:

#### 1. Employment as a contribution to society

Many of the participants in this study, including participants engaged in employment, seeking work, those without the right to work expressed a desire to be able contribute to society. Employment was an important means by which they felt they could achieve this. This is also a feeling expressed by people with disabilities from the majority ethnic group (Tubridy, 1996).

#### 2. Employment, integration and well-being

Some participants spoke about work in terms of their well-being. For some participants unemployment had affected their mental well-being:

'Before I came to work here, I was very down.'

Work was a way of overcoming depression and isolation, especially for those living alone. Employment was also important to those for whom the problem of impairment such as chronic pain or mobility difficulties was a daily reality, problems that would continue even if all disabling barriers in society were removed. For them employment was an important means of coping with these personal difficulties of impairment:

'Work is very important for me, because I live alone and if I was at home I would be bored and I would have more time to think about my disability. Work helps to forget about my disability. It's very important.'

Employment is also an important component in the construction of identity. In Ireland, employment has been identified as a key factor in facilitating integration into Irish society and its role in increasing a sense of belonging to the community has been emphasised (Interdepartmental Working Group on the Integration of Refugees in Ireland, 2000). Thus, unemployment and welfare dependency not only impede acculturation and integration but also undermine the right to a positive identity. Research has found that unemployment can affect psychological, social and general well-being as well as physical health (Begley et al, 1999). This raises particular concerns for those groups of asylum seekers who have to endure unemployment, as they do not have the right to work.

#### 3. Employment and economic benefits

Participants commented on the financial benefits of working:

'From the financial side as well, I get some money as well. Then I can save some and this is a benefit. I can save some money and have money for some extra things'.

Employment is an important way for people with disabilities from minority ethnic communities of earning income and raising their standard of living. It may be an important route for achieving economic independence.

# 5.3 Conclusion

The report shows that minority ethnic people with disabilities face exclusion and marginalisation in Irish society. One outcome of this is that minority ethnic people with disabilities often do not have adequate access to information about the availability of and their rights and entitlements to health and social care services. This may result in the under-utilisation by minority ethnic people with disabilities of health and social care services.

The assumption is often made in health services that it is the 'norm' for users to be 'able-bodied' and from the same ethnic, cultural and linguistic background as the wider Irish population. Minority ethnic people with disabilities, who diverge from this 'norm' in more that one way, can often face multiple barriers in accessing health services and may not have their needs adequately met. This is clearly illustrated in the report by an example revealing the multiple difficulties experienced by a minority ethnic deaf person in accessing health services in Ireland.

The report shows that health services do not always acknowledge that people with disabilities come from diverse ethnic backgrounds and many minority ethnic people with disabilities face linguistic and communication barriers to accessing health services. There is evidence from the study that Travellers with disabilities can encounter anti-Traveller racism within health services. Fanning (2002) has argued that institutional practices including within health services have limited capacity to 'conceptualise, identify and address' anti-Traveller racism. This has implications for other black and minority ethnic communities including those with disabilities. Fanning puts it in the following terms:

"There is legitimate concern that ... in areas such as education and health, asylum seekers along with other members of new immigrant communities may experience institutional barriers which resemble those encountered by Travellers." (2002: 173)

Asylum seekers and refugees with disabilities may be confronted with particular difficulties in accessing health services.

Employment represents an important route for people to achieve a higher socio-economic status. It is also important for promoting well-being, a sense of belonging and a sense of worth, from which a positive sense of identity arises. However, minority ethnic people with disabilities face a number of barriers in seeking to participate in the labour market and access employment. The barriers highlighted by participants include the low expectations of people with disabilities held by minority ethnic communities and by the wider society, physical barriers to accessing education and employment, lack of information and support services, exclusion from social contacts, geographical location and poor transport services. Participants were also aware of the potential for employers to discriminate against them. Such barriers can serve to undermine the socio-economic status and socio-cultural status of minority ethnic people with disabilities. Discrimination on the basis of ethnicity and disability are not the only difficulties preventing minority ethnic people with disabilities from participating in the labour market. For some participants, severe impairment or chronic illness presented difficulties, which would not be totally resolved with the removal of disabiling barriers in the area of employment. In addition, there are asylum seekers with disabilities in Ireland who do not have the right to work.

# **CONCLUSIONS AND IMPLICATIONS**

The situation, identity, and experiences of minority ethnic people with disabilities have not previously been considered within an Irish context. This is a small-scale, exploratory study. Drawing on a review of relevant literature, an examination of national statistical data and one-to-one in-depth interviews with nine participants as well as comments from health services staff the study provides some initial and useful insights into the situation, identity and experiences of minority ethnic people with disabilities in Ireland.

## 6.1 Situation, Identity and Experience

The report shows that minority ethnic people with disabilities are characterised by heterogeneity. Minority ethnic people with disabilities differ in terms of impairment. They comprise people with different types of impairments such as physical impairments, intellectual disabilities and sensory impairments. As with the wider population of people with disabilities, some minority ethnic people with disabilities may have congenital disabilities. Others may have acquired a disability due to disease, as a result of illness or longstanding health problems, or as a result of an accident. This is true for people with disabilities from indigenous minority ethnic communities and those from newly emerging minority ethnic communities, including asylum seekers and refugees. However, it is possible that asylum seekers and refugees may have acquired a disabilities come from diverse ethnic communities. Minority ethnic people with disabilities also differ according to a wide range of other factors including gender, age, sexual orientation, religion, citizenship status and family status. All of these have an impact on their situation, identity and experience.

#### The Situation of Minority Ethnic People with Disabilities in Ireland

Minority ethnic people with disabilities are largely an invisible group in Irish society and the situation of this multiple identity grouping is not easy to establish. This report shows how minority ethnic people with disabilities are often absent from national statistics. As a result, there are difficulties in trying to establish the numbers and social characteristics of minority ethnic people with disabilities using Irish statistical data. The absence of minority ethnic people with disabilities in statistics adds to the invisibility of this multiple identity grouping. The lack of data on minority ethnic people with disabilities in Ireland makes it difficult to establish the socio-economic status of this group of people. However, data from other countries shows that minority ethnic people with disabilities often experience double discrimination and can occupy a lower socio-economic status than other groups in society.

## The Identity of Minority Ethnic People with Disabilities

Minority ethnic people with disabilities hold multiple identities, and the concept of multiple identities is useful for reflecting the complexity of identity and experience of multiple identity groupings. The study set out to investigate how individuals holding multiple identities understand their identity and sense of belonging to different social groupings. The study found that minority ethnic people with disabilities perceive and understand who they are in different ways. Minority ethnic people with disabilities come from different ethnic backgrounds. They differ in terms of identification with minority ethnic groups and the extent to which they express ethnic identity. Minority ethnic people with disabilities do not always identify with the label 'disabled'. The report found that some minority ethnic people with disabilities reject a disability identity, which they may associate with a medical definition of disability. A deaf minority ethnic person adopted a cultural identity of the deaf community in place of a disability identity. Some minority ethnic people with disabilities understand the societal barriers that it presents. For some minority ethnic people with disabilities, identity and the experience of disability was not only determined by disabling attitudes and barriers in society, but also by the subjective experience of living with a physical impairment or health problem on a daily basis.

Recognition, which is concerned with respect for human dignity and for a person's cultural way of living, is considered to be important for people to develop a positive sense of identity. Misrecognition occurs where a person is either devalued, rendered invisible or subjected to disrespect by the dominant group and can undermine a person's sense of identity and who they are. The report first examined these in relation to the concept of single group identity. A person's single group identity can be simultaneously recognised and misrecognised. For example, a minority ethnic person may gain recognition of their ethnic identity by participating in shared cultural, linguistic and religious traditions of an ethnic group. At the same time, a person can be misrecognised on the basis of the same identity if the group to which they identify, is marginalised or discriminated against within the dominant culture. The devaluing of a group can have the effect of undermining a person's sense of identity. When the notion of multiple identities is introduced, issues of recognition and misrecognition become much more complicated. A person with multiple identities may hold an identity that is misrecognised within both the dominant and subordinate cultures. Or, a person with multiple identities may hold an identity that is at odds with the subordinate group with which that person identifies but is recognised by the dominant culture or another subordinate group. This can lead to ambivalence about an aspect of identity. Misrecognition can lead to difficulties and tensions not only between groups but also within groups.

## The Experiences of Minority Ethnic People with Disabilities

Minority ethnic people with disabilities can share common experiences because of their position in this social grouping. The study shows that minority ethnic people with disabilities can experience complex forms of discrimination. They can face discrimination on the basis of disability. This can lead to isolation, segregation and marginalisation. This is an experience they share in common with people with disabilities in the wider community. In addition to facing disablism in the wider community, minority ethnic people with disabilities may also encounter negative perceptions of disability within their own minority ethnic communities. Unlike people with disabilities in the wider community but in common with members of their own minority ethnic communities, minority ethnic people with disabilities are open to discrimination on the basis of ethnicity by the dominant culture. Vernon (1998) has referred to the experiences of minority ethnic people with disabilities as a form of simultaneous oppression. The experiences of specific groups of minority ethnic people with disabilities of post-migratory stress including issues around citizenship, separation from families, poverty, employment and accommodation issues.

# 6.2 Implications for Service Providers

People in Irish society have traditionally been considered to be a homogenous group of people. This way of thinking is reflected and reproduced in all Irish institutions, including in health and disability services. 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 'ablebodied' and from the same racial, cultural and linguistic background as the rest of the white majority Irish population. Just as in the wider society, minority ethnic people with disabilities are rendered invisible or viewed as 'atypical' both as users and providers in health and disability services.

Minority ethnic people with disabilities face barriers to participating in many areas of Irish society on the basis of ethnicity and disability. In a similar way to people with disabilities in the wider community, they face disabling barriers to accessing health and disabilities services. Such experiences can lead to exclusion and disempowerment and need to be addressed by health and disability services.

In Ireland there are services that are targeted specifically at people with disabilities. However, people with disabilities are not a single unitary group of people. Ethnicity is one way in which people with disabilities differ. This has implications for health and disability services. One of the challenges facing health and disabilities services in Ireland is for them to recognise and acknowledge the ethnic diversity of people with disabilities. Health and disability services need to develop an understanding of the cultural beliefs, practices and needs of minority ethnic people with disabilities. A failure to respond effectively to minority ethnic people with disabilities can result in the provision of culturally inappropriate health and disability services. Barriers experienced by participants and highlighted by health service providers point to the importance of providing culturally competent health services. Cultural competency may be defined as:

- the understanding that culture profoundly influences an individual's health beliefs, practices, behaviours and the outcomes of health care
- · responding respectively and effectively to people of all cultures
- affirming the worth and dignity of individuals, families and communities

Minority ethnic people with disabilities can often face multiple barriers in accessing health services so that their needs are not adequately met. This is clearly illustrated in the report by an example revealing the multiple difficulties experienced by a minority ethnic deaf person in accessing health services in Ireland.

The problem of direct or overt racism as encountered by minority ethnic people with disabilities in Irish society was raised in the study. Racism can also be reflected in institutions such as health and disabilities services. Institutional racism is considered to be a factor preventing minority ethnic people with disabilities from accessing services and can lead to isolation and exclusion for them and their families. Institutional racism experienced by minority ethnic people with disabilities and their families trying to access health and disability services can take subtle and distinctive forms. There is evidence from the study that Travellers with disabilities may be confronted with anti-Traveller racism within health services. Health and disability services need to acknowledge and address the existence of institutional racism, both historically and contemporarily, and to develop the capacity to address prejudice among staff in their organisations.

People may be categorised as minority ethnic people with disabilities, 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. 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 report notes the absence of minority ethnic people with disabilities from health data monitoring systems in Ireland. The availability of data within health services on this social grouping would make it easier to plan and monitor health services for minority ethnic people and people with disabilities. However, in some circumstances minority ethnic people with disabilities may choose not to disclose

certain aspects of their identity. This choice would be respected by ensuring that principles of selfdetermination and choice are hallmarks of all health and disability data collection systems.

Voluntary and community organisations of and for people with disabilities have an important role to play in advocating the concerns, views and contributions of people with disabilities in relation to health and disability services. The inclusion of minority ethnic people or at least the concerns of minority ethnic people in disability advocacy mechanisms may go some way to addressing the barriers identified in this report.

In a similar way, groups and organisations representing minority ethnic people have a role to play in highlighting the barriers facing minority ethnic people in accessing health services. The access of minority ethnic people with disabilities to health services could be improved if these groups and organisations were to take account of issues facing people with disabilities when promoting the rights of minority ethnic groups.

There appears to be insufficient training of health services staff on the issues facing minority ethnic people with disabilities in accessing health services. None of the health services staff contacted had any form of training in this regard. Some health services staff working with people with disabilities had been in contact with or felt that they were likely to come into contact with minority ethnic people with disabilities and commented that training on issues facing minority ethnic people with disabilities would be welcome and useful.

One of the challenges facing health and disability services is to develop an awareness of the assumptions that inform organisations and their practices. There needs to be an openness to challenging and redefining such deep-rooted assumptions. Health service staff bring their own cultural perspective to their work. In addition, they may have a limited understanding of the cultural framework of people from a different background. A lack of understanding of the issues facing and needs of people with disabilities from minority ethnic communities can lead to culturally inappropriate service provision or a service which is insensitive to minority ethnic people with disabilities (French, 1994). This may relate to practical things, such as the provision of appropriate food or the way their skin and hair is taken care of in day care, hospital or residential services (Shah and Priestley, 2001). Disabled people and their carers are less likely to accept assistance if services do not cater for their particular cultural needs. Providing culturally competent services involves overcoming gaps between different groups of people and entails openness, observation, listening, learning and redefining one's viewpoints. These strategies can be used in working with people with disabilities, minority ethnic people and people with disabilities from minority ethnic communities. Culturally competent health services involve taking into consideration people's cultural needs. They ensure that communication is culturally appropriate. They give people time. They challenge and address prejudice, discrimination and inequalities.

# 6.3 Implications for Employment Strategies

The marginalisation of people with disabilities in Irish society is reflected in their low level of participation in the labour market. Minority ethnic people with disabilities face a number of barriers in seeking to participate in the labour market and access employment. The barriers highlighted by participants include the low expectations of people with disabilities held by minority ethnic communities and by the wider society, as well as physical barriers to accessing education and employment. For minority ethnic people with disabilities, 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. Racism and disablism can be reflected in the workplace, such that people with disabilities from minority ethnic communities may potentially face discrimination from employers on two fronts, that is ethnicity and disability.

Discrimination against minority ethnic people with disabilities can occur in spite of equality legislation in the area of employment. Equality practices in enterprises aimed at preventing discrimination across all nine equality grounds in the recruitment of employees as well as in the workplace are crucial for achieving equality for minority ethnic people with disabilities in the area of employment. In addition, employers need to recognise and take account of the fact that employees or potential employees may differ on more than one equality ground. The needs of and issues facing minority ethnic people with disabilities in accessing the labour market and participating in employment could be highlighted in training and policies targeted at employers and employer organisations.

For some minority ethnic people with disabilities, severe impairment or chronic illness presented difficulties, which would not be totally resolved with the removal of disabling barriers in the area of employment. This issue affects people with disabilities in the wider community and is an issue that has received little attention in Ireland and requires further research. In addition, there are asylum seekers with disabilities in Ireland who do not have the right to work.

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