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Ollscoil Chathair Bhaile Átha Cliath



# **Hear My Voice: the experience of discrimination of people with mental health problems in Ireland.**

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Dublin City University  
Glasnevin  
Dublin 9

Tel: +353 (0)1 700 5000  
[www.dcu.ie](http://www.dcu.ie)

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# Hear my voice: the experience of discrimination of people with mental health problems in Ireland.

## **Authors**

Dr Lám Mac Gabhann  
Dr Richard Lakeman  
Mr Paddy McGowan  
Dr Michael Parkinson  
Ms Muriel Redmond  
Dr Ingrid Sibitz  
Prof Chris Stevenson  
Mr Jim Walsh

**Dublin City University**  
**October 2010**



<sup>1</sup> Please address correspondence to Dr Liam Mac Gabhann, School of Nursing, Dublin City University, Glasnevin, Dublin 9; liam.macgabhann@dcu.ie.

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In 2010 Amnesty International Ireland (AI) commissioned a research study on the experience of discrimination by people with mental health problems. Following an open tender a research team from the School of Nursing at Dublin City University (DCU) was awarded the research contract. The aim of this research was to provide substantive qualitative and quantitative findings relating to the experience of discrimination as reported by people with mental health problems. This research informs AI's accompanying campaign briefing document Hear my voice: challenging mental health prejudice and discrimination and the messaging of the organisation's campaign to challenge mental health prejudice and discrimination.

The opinions and findings of this report are those of its authors and do not constitute AI policy.

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Prof. Chris Stevenson  
Principal Investigator

Dr Liam Mac Gabhann<sup>1</sup>  
Project Manager

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### Summary of Key Findings

- Nearly everyone who participated in the study (95.4 per cent; N=292) reported some level of unfair treatment as a result of a mental health problem.
- On average, participants reported unfair treatment in 41 per cent of the 21 items of the unfair treatment scale.
- The five highest incidences of reported unfair treatment related to making or keeping friends (64 per cent); having been treated unfairly by family (61 per cent); being avoided or shunned by people who knew participants had a mental health problem (63 per cent); being treated unfairly by mental health staff (58 per cent) and being treated unfairly in your role as a parent (46 per cent).
- Participants reported being treated unfairly in relation to finding a job (36 per cent) and keeping a job (43 per cent). When considering the examples given by people who felt treated unfairly in relation to their social life that frequently related to their work environment, the extent of unfair treatment to do with employment is further underlined.
- Being hospitalised and prescribed medication was associated with higher reports of unfair treatment against most of the 21 items. Different types of medication affected reports of unfair treatment differently.
- The majority of participants (86.2 per cent) reported experiencing distress due to their perception of being discriminated against because of their mental health problem. More than half of participants reported experiencing 'a lot' of distress as a result of discrimination.
- More than 70 per cent of participants concealed their mental health problems from others. Three in five stopped themselves from working. More than half stopped themselves from having a close relationship and more than 40 per cent of people stopped themselves engaging in education.
- Participants also provided reports of more positive treatment due to their mental health problems, particularly by family and in health care.

## **Introduction**

Throughout the world, people with mental health problems face persistent and pervasive discrimination, resulting in the denial of their human rights, and profound social and economic exclusion (Kelly, 2006; Sayce, 2000; Thornicroft, 2006). In Ireland one of the strongest concerns voiced both by service users and providers in consulting on the national mental health policy A Vision for Change (AVFC; Department of Health and Children, 2006) was the problem of stigma and discrimination and their contribution to social exclusion including loss of employment, education and secure housing. These concerns are echoed in debates about mental health policy across the world (e.g. Department of Health and Human Services, 1999; New Zealand Mental Health Commission 1997; Royal College of Psychiatrists, 2009; Social Exclusion Unit, 2004; World Health Organisation, 2001; World Health Organisation Europe, 2005).

According to the World Health Organisation, the stigma and associated prejudice and discrimination that exist towards people with mental health problems is one of the most important issues to overcome in mental health policy (World Health Organisation, 2001). This is reiterated in the Mental Health Declaration for Europe which includes the aim to 'collectively tackle stigma, discrimination and inequality and empower and support people with mental health problems and their families to be actively engaged in this process' (World Health Organisation Europe, 2005).

A prerequisite for achieving the aim of the Mental Health Declaration for Europe is the availability of strong, systematic research that examines the way in which people with mental health problems experience discrimination. This report aims to explore this in an Irish context by conducting interviews with people with experience of mental health problems and asking them to identify the nature and extent of discrimination, defined as unfair treatment, that they perceive in their lives.

## Chapter 1: Literature Review

### Introduction

<sup>2</sup> For a review see Link and Phelan (2001)

The purpose of this chapter is to set out existing research and concepts, and how they relate to discrimination. Within the mental health field, a large academic literature has developed around areas related to discrimination (see Aichberger and Sartorius, 2006), viewed most frequently through the lens of 'stigma'. As will be explained further below, 'stigma' is a wider concept that encompasses processes that extend beyond discrimination. Therefore, after a discussion of stigma and its usage within the field of mental health, this chapter will then break the concept of stigma into concepts of stereotypes, prejudice and discrimination. Links are then drawn between this understanding and the data that already exists about the nature and occurrence of stereotypes, prejudice and discrimination.

### Stigma

*"There is no known country, society or culture in which people with mental illness are considered to have the same value and to be as acceptable as people who do not have mental illness."*

Graham Thornicroft, Shunned

As Thornicroft (2006) argues, any interest in the social processes that push people with mental health problems to the margins of society must begin by looking at what has been written about stigma. Goffman's founding work on stigma (1963) was foreshadowed by his inquiries into the sociology of mental health problems (1991) and share a common intellectual source. It is understandable then that the link between stigma and mental health has remained long after its application to other conditions, such as disability or HIV/AIDS, was questioned and rejected (e.g. Fine and Asch, 1988; Oliver, 1990; Parker and Aggleton, 2003) and even after it has been subject to critique and reconceptualisation within the field of mental health itself (e.g. Sayce, 2000; Link and Phelan, 2001; Thornicroft, 2006).

The literature on stigma, using Goffman as its anchor, typically relies on the definition of stigma as "an attribute that is significantly discrediting" shifting our view of the person "from a whole and usual person to a tainted, discounted one" (1963, p. 3). Jones et al. (1984) later described stigma as a 'mark' that was associated with discrediting dispositions while Crocker and colleagues propose that stigmatisation occurs where a person possesses or is thought to possess "some attribute or characteristic that conveys a social identity that is devalued in a particular social context" (Crocker et al., 1998, p. 505). Clustering around these definitions, research on stigma has grown rapidly and been applied across a huge variety of domains including mental health but also physical and mental disabilities, sickness and disease, HIV/AIDS, sexual behaviour, welfare dependency, unemployment and many others<sup>2</sup>. This has provided a wealth of knowledge about the detrimental impact of stigma in the lives of those who are stigmatised and provided a rich seam for exploration by scholars, clinicians, service-users and campaigners alike.



<sup>3</sup> For example, in the field of HIV/AIDS Parker and Aggleton (2003) argue current work that views stigma as a static attitude unfaithfully represents Goffman's views which were bedded in ideas of social change and shifting interpersonal relations. The same may be applied to much work on mental health.

<sup>4</sup> Though for criticism of the disability-inclusion model as it is applied to mental health, see Sayce, 2000.

<sup>5</sup> The CRPD defines disability to include any long-term mental impairment "which in interaction with various barriers may hinder ... full and effective participation in society on an equal basis with others" (Article 8).

However, there remains a great deal of uncertainty as to what the term stigma actually means. As Link and Phelan (2001) explain, definitions, if they are given, tend to rehearse, often inaccurately<sup>3</sup>, that given by Goffman (1963) or rely on standard dictionary definitions. Where attention is paid to clearly defining stigma, there is great variance across studies, no doubt due to the varying domains in which it has been applied and the multiple disciplines that have applied it. This may lead to the problematic situation highlighted by Sayce (1998), that in applying the term stigma too loosely, researchers and advocates lose the capacity to properly articulate solutions, or mask other problematic, perhaps more damaging, processes that may be co-occurring.

Other sources of criticism have emanated from the disability politics movement (Fine and Asch, 1998; Oliver, 1990). Fine and Asch criticise the fact that stigma is rarely examined from the perspective of the 'stigmatised' which gives rise to several persistent myths propagated by the stigma paradigm. These are that: a) disability is located solely in biology; b) the problems of disability are due to disability-produced impairment; c) the disabled person is a 'victim'; d) disability is central to the person's self concept; and e) disability is synonymous with needing help and social support. While many people with mental health problems do not perceive themselves as having a disability, many of the myths listed above are commonly articulated in discussions about the treatment of people with mental health problems<sup>4</sup>. Such a view of 'victims' of stigma is also in stark opposition to approaches, such as that adopted by the UN Convention on the Rights of Persons with Disabilities (which includes people with mental health problems) which presents a social approach to disability that rejects a view of persons with disabilities as 'objects' of charity and treatment and instead places them as 'subjects' with rights, who are capable of claiming those rights and making decisions for themselves<sup>5</sup>.

A related point is that stigma research has been individualistic in its focus and has focused on the wrong individuals. This is supported from a host of perspectives including sociology (e.g. Link and Phelan, 2001), social psychology (e.g. Fiske, 2000), the disability rights movement (Oliver, 1990); other areas of health research where the stigma concept is applied (e.g. Parker and Aggleton, 2003) and now, increasingly within the mental health literature (Sayce, 1998; 2000; Thornicroft, 2006). Broadly speaking to date research has viewed stigma as an attribute, thereby locating the problem within the individual, rather than the result of others attaching a stigmatising label to the person. Moreover, this approach has provided little by way of knowledge about the structural processes (e.g., economics, politics, legislation) that work to exclude certain people from social and economic life (Oliver, 1990). As Sayce (1998) points out, what we mean by the term stigma has implications for different understandings of where responsibility lies for the 'problem' and for the actions we prescribe as solutions.

Recent theoretical and empirical work within the mental health literature has tried to answer these criticisms, either through reinterpreting the concept of stigma or moving beyond it (see next section). Common threads in this work have been: the attempt to identify the different levels at which stigma

may operate; bringing the voice of people with mental health problems to the fore; focusing on the acts of discrimination that people with mental health problems report; and making a link to the language of rights in order to identify constructive solutions.

### **From Stigma to Stereotypes, Prejudice and Discrimination**

Link and Phelan (2001) provide a comprehensive critique of stigma theory and research. Their theoretical reworking aims to bring greater clarity to the concept of stigma and account for the multiple processes that appear to be involved. They define stigma as occurring “when elements of labelling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows the components of stigma to unfold” (Link and Phelan, 2001, p. 367). This was a useful reworking in distinguishing that stigma may be the amalgam of a variety of different processes, shifting the emphasis beyond attitudes, which has typically dominated stigma research, and bringing a focus to discriminatory behaviour. This moves usefully beyond ‘victim blaming’ tendencies and emphasises patterns of social and economic exclusion and the active denial of rights and entitlements as advocated by Sayce (1998).

Corrigan and Watson (Corrigan, 1998; Corrigan and Watson, 2002), drawing on work in social psychology (e.g. Fiske, 2000), offer a tri-partite model of what they call public stigma; that is, the reaction that the general public have to people with mental health problems. The three components are stereotypes (widely held and persistent beliefs about a group), prejudice (agreement and emotional reaction to belief), and discrimination (behavioural response to prejudice). The consequences of these processes include loss of “work, independent living and other important life opportunities” (Corrigan and Watson, 2002, p. 35).

Thornicroft (2006) adopts a similar tri-partite approach in his re-working of the stigma concept. He views stigma as an overarching term that covers three domains: problems of ignorance (leading to myths and stereotypes); problems of attitudes (leading to prejudice); and problems of behaviour (leading to discrimination). He surveys the existing stigma literature from this vantage point, notes the paucity of research on discrimination and concludes that it is in precisely this area that we must now focus.

### **Stereotypes**

Stereotypes are negative perceptions of others that are generally widely held and well known among members of a given society or culture, and become the basis for avoiding, excluding or even persecuting members of the stereotyped group (Major and O'Brien, 2005).

A variety of negative stereotypes about mental health problems have been identified in the literature that are firmly held in societies but not supported by evidence. These include the stereotypes that people with mental health problems are dangerous, frightening, unintelligent, unreliable, incapable of work, unreasonable, unpredictable, incomprehensible or lacking in will power or self-control or that mental health problems are impossible to recover from, only affect certain kinds of people or are equivalent to intellectual

disabilities (Crisp et al., 2000; Fazel and Grann, 2006; Klin and Lemish, 2008; Thornicroft, 2006).

There is some suggestion that providing greater, more accurate, information about mental health problems could combat negative stereotypes of people with mental health problems. However, work in this field, sometimes referred to as 'mental health literacy' has provided contradictory evidence. Jorm et al. (2006) have shown that even where there is evidence for greater public knowledge of mental health issues, this does not lead to uniform decreases in negative perceptions about people with mental health problems. Phelan et al. (2000) observed a broadening of popular understandings of mental health in the USA over a 40 year period but witnessed a two-fold increase among the general population in the perceived link between mental health problems and 'frightening characteristics' such as extreme or unstable behaviour. Interestingly they also found differences across types of mental health problems, with 'psychotic disorders' (i.e. schizophrenia) perceived as more dangerous than 'non-psychotic disorders' (i.e. anxiety or depression).

Similarly in the UK across the nineties, the perception of people with mental health problems as different from 'normal people' fell while the perception of fear, threat and danger from people with mental health problems increased (Department of Health, 2003). Subsequent research showed once again that diagnosis was an important factor in shaping people's views with perceptions of difference, recovery and danger varying depending on what condition was ascribed to an individual in a series of questions (Crisp et al., 2000). Finally, research into what is termed 'self-stigma' has shown that people with mental health problems themselves can retain stereotyped views about mental health problems (e.g. Watson et al., 2007).

As can be seen, the common stereotypes of people with mental health problems as different, dangerous and threatening form a core part of societal understanding of this group of people and contribute to constructs of 'them' and 'us'. Despite growing mental health awareness, many of these stereotypes are difficult to eradicate and are embedded in public consciousness particularly strongly for certain mental health diagnoses like schizophrenia. The misunderstanding, mistrust, and fear that arise from such faulty social categorisation can spur strong, negative affective responses in people's attitudes towards those who they perceive as different.

### **Prejudice**

Prejudice has its origins in the social psychology of Gordon Allport (1954) who defined it as "an aversive or hostile attitude toward a person who belongs to a group, simply because he belongs to that group, and is therefore presumed to have the objectionable qualities ascribed to that group" (p. 7). Classical studies on prejudice focused on 'race' and more latterly gender and age. The use of the term in relation to mental health has been rarer (Stuber et al., 2008) though in actual fact, much of the research that has been carried out on the stigma of mental health – focusing on the attitudes and beliefs of the general population toward people with mental health problems – could readily be classified as prejudice research (Phelan et al., 2008).

<sup>6</sup> Vignette studies ask for participants' responses to a description of series of scenarios in order to gain information on attitudes to a particular issue. Social distance scales measure participants' willingness to engage in social contacts of different levels of closeness with members of a particular social group.

<sup>7</sup> For this see Thornicroft (2006), Aichberger and Sartorius (2006) or NDA (2007).

Evidence from over half a century of research including public attitudes surveys, vignette studies and social distance<sup>6</sup> scales has shown a persistently negative picture of the attitudes and anticipated responses that the general population have toward people with mental health problems. Space does not allow a full examination of this here<sup>7</sup> but some general trends can be highlighted.

Examples of prejudicial attitudes uncovered in the general population include not accepting a person with mental health problems in intimate relationships, as a babysitter, flatmate or neighbour or recommending him or her for a job (Corrigan et al., 2001; Angermeyer and Matschinger, 2005; Schomerus et al., 2006; Grausgruber et al., 2007; Law et al., 2009; TNS, 2007). Angermeyer and Dietrich (2006) conducted a comprehensive review of population-based studies of attitudes to mental health and found that, since the beginning of the 1990s negative attitudes continue to prevail among the general public. They conclude that a substantial part of the population in countries for which data is available perceive people with mental health problems as unpredictable and dangerous and react to them with fear. They also found indications of inter-cultural variations of beliefs and attitudes as well as of changes over time. The review showed marked differences between the various mental health problems with regard to beliefs and attitudes. Schizophrenia is viewed more negatively than depression or anxiety.

Interestingly, in opposition to what the health literacy theory would predict, the wish for social distance is also quite prominent among psychiatrists and mental health professionals (Jorm et al., 1999; Kingdon et al., 2004; Lauber et al., 2004a; Schulze, 2007). While personal experience with people with mental health problems can reduce prejudice in the non-medical sector (Lauber et al., 2004b), the relationship in the health-care-sector is more complicated (Ross and Goldner, 2009; Schulze, 2007; Bjorkman et al., 2008). Caldwell and Jorm (2001) for instance found that psychiatrists and mental health nurses have more pessimistic attitudes towards the probability of discrimination and the prognosis of schizophrenia and depression compared to the general public or other non-specialists.

There has been some evidence recently in the UK to suggest that attitudes may be becoming worse. The 2007 'Attitudes to Mental Illness' survey (TNS, 2007) found an increase in prejudice across a wide variety of indicators, including not wanting to live next door to someone who has had a mental health problem, not believing that people with mental health problems have 'the same right to a job as anyone else', and believing that people with mental health problems are 'prone to violence'.

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### **Attitudes toward people with mental health problems in Ireland**

Attitudes toward people with mental health problems have received some attention in an Irish context and for the purposes of this report we will examine this in a little more detail.

In examining the social exclusion of people with mental health problem, the National Economic and Social Forum (NESF, 2007) cited evidence that a majority of people in Ireland, both with and without mental health problems,

believe that there is at least some social stigma attached to mental illness. It also reported that the provision of mental health services in the local community is still regarded with caution by the general public due to a fear of threat to their safety. Mental Health Ireland carried out surveys in 2003 and 2005 which found that, while positive attitudes predominate and those with negative attitudes are in the minority, there is still room for significant improvement particularly among males, older people (65+) and younger people (under 25) and among lower socio-economic groups.

High levels of prejudicial attitudes were found in a series of national surveys over recent years. The Health Service Executive (HSE) report *Mental Health in Ireland: Awareness and Attitudes* (HSE, 2007) shows that one fifth of people thought that people with mental health problems should not have the same rights as anyone else. The majority of people interviewed (62 per cent) would not want others knowing if they themselves had a mental health problem and over half (52 per cent) believed that people with mental health problems should not do important jobs such as being a doctor or a nurse. In addition, more than one third (36 per cent) agreed that people with mental health problems are often dangerous.

This survey was replicated more recently as part of the baseline data for a new national anti-stigma campaign, *See Change*, the National Mental Health Stigma Reduction Partnership (2010). This showed that Irish people underestimate the prevalence of mental health problems and only two out of three people strongly agree that people with mental health problems should enjoy the same rights as others. On average, less than half of people surveyed thought people with mental health problems should have children. It also found that attitudes differed depending on diagnosis with attitudes toward someone with a diagnosis of schizophrenia more negative than for depression. When asked whether someone with a diagnosis of schizophrenia was likely to harm him or herself 42 per cent of people agreed and 31 per cent agreed he or she would be likely to harm someone else. The figures for a person with a diagnosis of depression were 30 and 16 per cent respectively.

### **Discrimination**

Despite the volume of knowledge that has been generated by research into prejudiced attitudes toward people with mental health problems, Thornicroft (2006) questions the value of this work in providing clear recommendations for intervening and reducing persistent discriminatory behaviour and thereby bringing about positive change in the lives of people who are the subject of these prejudices. These types of research have typically provided us with a view of what the wider public think about people with mental health problems, rather than the experiences of people with mental health problems themselves, and rely on indirect assessment of behavioural intention (i.e. what people say they will do, rather than what they actually do). Commenting from a social psychological perspective, Fiske (2000) argues that there is a great lack in terms of definitive evidence about the behavioural outcomes of such prejudices and that not enough attention is paid to the kinds of contextual factors that mediate the actual experience of discrimination, including social



roles, relationships, norms, accountability and power.

<sup>8</sup> For a review of the way mental health is under-represented in cases taken under existing anti-discrimination laws in the UK and the US see Glozier, (2004), and Pardeck, (1998)

Discrimination relates to the actual experience of unfair treatment and is seen as a behavioural response based on prejudice (Corrigan and Watson, 2002; Thornicroft, 2006). Given its relative neglect to date, the literature on discrimination against people with mental health problems is somewhat less than that on attitudes, though the issue of discrimination is growing and moving more toward the centre of concern for professionals, service users and advocates (Arboleda-Florez, 2005). Estroff et al (2004), in their review of anti-stigma and anti-discrimination programmes in the US, have noted a shift “from a focus on stigma associated with illness per se toward the vocabulary of discrimination, including an emphasis on human and civil rights and empowerment and self-advocacy” (p. 505). Two comprehensive works to date give compelling arguments for the existence of discrimination against people with mental health problems and have brought the issue into greater relief. Sayce (2000) and Thornicroft (2006) provide evidence from across the globe of discriminatory patterns targeting people with mental health problems across multiple domains including family and parenting rights, friendship and intimate relationships, social life, employment, housing, immigration, insurance, health and social care, the media and the justice system.

Thornicroft (2006) identifies a number of advantages to this new direction of research. First, it represents a move from studying attitudes and asking what people would do, to studying actual behaviour. As Fiske says, “thoughts and feelings do not exclude, oppress and kill people; behaviour does” (p. 312, 2000). Second, we can use this data to see whether interventions are effective in combating the occurrence of discriminatory behaviour. We can also use information about discrimination based on mental health problems to shape and target existing or new anti-discrimination laws to the full benefit of people with mental health problems<sup>8</sup>. In summary, this shift requires “sharpening our sights upon human rights, injustice and upon discrimination as actually experienced by people with mental illness” (Thornicroft, 2006, p. 191).

### **Evidence of Discrimination Against People with Mental Health Problems**

Over the past decade or so a number of empirical studies in different countries have sought to assess the level of discrimination experienced among people with mental health problems. In all cases the research relies on self-report of perceived unfair treatment or discrimination which can be problematic (European Commission, 2007; Major et al., 2002). However in some studies, additional qualitative data were provided that allowed some corroboration of self-reports.

Read and Baker (1996), carrying out a study in the UK for the mental health charity Mind, surveyed 778 mental health service users and found a high prevalence of perceived discrimination. Almost half (49 per cent) of respondents reported being attacked or harassed in public. 62 per cent reported unfair treatment by family or friends and 50 per cent perceived unfair

treatment in the realm of general health care while 34 per cent reported being dismissed or forced to resign from jobs and 38 percent reported harassment at work due to their psychiatric history. More than a quarter (26 per cent) of men and 48 per cent of women believed their parenting capabilities had been unfairly questioned due to their mental health problems.

In the United States, a systematic study of 1,824 people recruited from community mental health centres examined perceived discrimination across a variety of personal factors and in multiple domains of life (Corrigan et al., 2003). All participants had received a diagnosis of a mental illness and reported at least two associated hospitalisations. Over half of respondents reported discrimination of any kind (i.e. due to mental illness, race, gender, sexual orientation, economic circumstances or for some other reason). Of people who reported discrimination 73 per cent (or 37 per cent of the total sample) reported that it was due at least in part to mental illness. This was higher than other factors with, for example, poverty identified as a cause by 51 per cent of those who perceived discrimination. Employment (51.7 per cent) was the most frequently cited area of experienced discrimination for people with mental health problems followed by housing (32.3 per cent) and about a quarter reported discrimination in the areas of traditional mental health services (27.5 per cent), law enforcement (26.9 per cent) and education (23.7 per cent).

In New Zealand, Peterson et al. (2007) administered a questionnaire to 785 people who self identified as having experienced mental health problems. The questionnaire asked whether or not people had ever experienced discrimination because of mental illness in 13 different areas (e.g. employment, education and training, housing, mental health services etc.) Discrimination was self-defined by the participants. Participants were also asked to provide details of what happened and when it occurred. Rejection by friends and family was the most commonly reported (59 per cent) experience of discrimination. About a third reported discrimination in the areas of employment (34 per cent), community (32 per cent reported hostility and harassment) and mental health services (34 per cent), and between a quarter and a fifth reported discrimination in government agencies (27 per cent), financial institutions including bank and insurance companies (20 per cent), general health services (23 per cent), parenting (24 per cent) and education (21 per cent). Discrimination in the area of housing was reported by 17 per cent of participants.

Thornicroft and colleagues (Thornicroft et al., 2009) assessed the experienced and anticipated discrimination against people with schizophrenia in 27 countries around the world (732 participants). They found that negative discrimination was experienced by 47 per cent of participants in making or keeping friends, by 43 per cent from family members, by 29 per cent in finding a job, 29 per cent in keeping a job, and by 27 per cent in intimate or sexual relationships. A further 19 per cent felt unfairly treated in education, 17 per cent by the police and 14 per cent in housing. Anticipated discrimination affected 64 per cent in applying for work, training, or education and 55 per cent when looking for a close relationship. 72 per cent of participants felt the need to conceal their diagnosis. The amount of negative discrimination

was predicted by treatment duration and experience of coercive measures.

### **The personal impact of discrimination**

The social and economic impacts of discrimination have been observed in the stigma literature. For example, what Corrigan et al. (2004) call structural stigma is linked with un- or under-employment (Corrigan et al., 2004; Drake et al., 1999), poorer treatment (Wang et al., 2000) and poorer quality of life (El-Badri and Mellsop, 2007).

However, discrimination can impact at the personal level as well. Gostin (2000) suggests that just as human rights violations can take their toll on mental well being, so too persistent and systematic discrimination has a damaging effect on the mental health of people who experience it. While little work has been done on this to date with specific regard to discrimination, the broader stigma literature clearly demonstrates the harsh burden for both the person affected and family members (Stuart, 2008) which compounds that already caused by the mental health problem (Finzen, 2009; Corrigan et al., 2009).

At an individual level, the internalisation of stigma – that is, the application of negative stereotypes and stigmatising attitudes to oneself – also has an impact (Corrigan, 1998; Ritsher et al., 2003). As well as making it even more difficult to overcome already existing barriers to entering relationships, employment and housing, and hindering the recovery process (Amering and Schmolke, 2009) this internalisation has been found to be associated with depression and anxiety as well as a reduction in hope, self-esteem, empowerment and quality of life (Berge and Ranney, 2005; Lysaker et al., 2008, 2009; Mak et al., 2007; Ritsher et al., 2003; Vauth et al., 2007; Watson et al., 2007; Yanos et al., 2008). The specific relationship between discrimination and indices of mental health also merits further consideration in the context of the current study.

Currently research in an Irish context is focused only on attitudes toward people with mental health problems. We know very little about the lived experience of people with mental health problems. We also know little about the way in which people with mental health problems react when they experience discrimination, or their awareness of the support and redress mechanisms that exist. By carrying out this study we hope to provide information for some of the current gaps in knowledge about discrimination in Ireland, including:

- Providing qualitative and quantitative evidence for the extent, nature and sites of unfair treatment experienced by people with mental health problems.
- Measuring the impact of the experience of unfair treatment on the lives of people with mental health problems.
- Providing evidence for the levels of awareness of anti-discrimination redress mechanisms and support services.
- Providing evidence for any differences in the experience of unfair treatment according to demographic variables and personal mental health history.



## Chapter 2: Methodology

The current study seeks to expand the understanding of the relationship between mental health and discrimination, defined as unfair treatment, in an Irish context. It is located within recent developments in mental health literature that has placed an emphasis on discrimination, defined as “the behavioural consequences of stigma which act to the disadvantage of service users” (Thornicroft, 2006, p. 182). Research as to how people with mental health problems experience discrimination is still in its infancy (Bjorkman et al., 2006). Building on earlier qualitative work, a number of efforts have been made to develop reliable and valid instruments to measure the experience of discrimination and allow comparison across different settings and culture (Schulze and Angermeyer, 2003; Lee et al., 2006; Gonzalez-Torres et al., 2007; Peterson et al., 2007; Thornicroft et al., 2009; see Brohan et al., 2010 for a review of 14 different scales).

This study uses version 12 of Thornicroft et al.’s (2009) Discrimination and Stigma Scale (DISC). The scale is based on Thornicroft’s (2006) theoretical work which defines discrimination as the unfair treatment of people who have a mental health problem. The scale aims to provide a measure of people’s self-reported experience of discrimination by asking them to identify and describe examples of ‘unfair treatment’. The DISC has been applied as part of a major world wide study into experiences of discrimination among people with schizophrenia across 27 different countries (Thornicroft et al., 2009) and is currently being used in an updated form (DISC 12) to evaluate the impact of the Time to Change anti-discrimination campaign in the UK (Henderson and Thornicroft, 2009). This scale was chosen for the purposes of operationalising discrimination in this study for a number of reasons. Firstly, it explores discrimination from the perspective of people with experience of a mental health problem. Secondly, as a survey-based instrument, the DISC facilitated a large-scale study as was required for the current research. Finally, using this scale has enabled comparison of the results of the current study with similar research elsewhere.

The methodology chosen for this study was Participatory Action Research (PAR). PAR differs from traditional research methodologies, as: (a) the (PAR) research process generates knowledge about the social system under investigation while also attempting to transform it; (b) the community under investigation are active co-researchers in the process; and (c) the cyclical approach provides a process of constant critical reflection on the topic (discrimination) and emerging data. In addition, PAR has a long and well developed history of effectively researching within vulnerable and disenfranchised groups, including people with mental health problems (Greenwood and Levin 1998; Borda 2001; Hummelvoll and Seviensson 2005; Koch and Kralik 2006; Reason and Bradbury, 2008). PAR requires the active participation of members of the community under investigation and would view non-involvement as unethical and contrary to the philosophical principles of the methodology (Reason and Bradbury, 2008). In practice, this means that in addition to having an emancipatory intent to the research, it should aim to include members of the researched community in all phases

of the research from design to dissemination as well as providing client group researchers with payment for their services (Faulkner, 2004).

This is also in line with recent shifts in the way that research in mental health is perceived and carried out (Sallah and Clark 2005). People with mental health problems no longer accept being objects of research or succumbing to research methodologies that do not necessarily reflect their experience. More often they seek to lead and participate in the research as equals rather than passive recipients of disempowering research processes (Faulkner and Thomas 2002; McGowan and Mac Gabhann et al. 2009). PAR aims to provide a democratic, empowering and inclusive methodology for inquiring into the lives of people with mental health problems. Finally, as this was the first study of its kind in Ireland, it was necessary that the methodology was sufficiently flexible to tease out various aspects of possible discrimination.

## Participants

### Sample

A total of three 306 participants were interviewed for this study. Relevant details are summarised in Table 1.

**Table 1. Profile of Participants**

#### Average Age\*

43 years (range = 19 – 75 years)

#### Sex

Men	47 %
Women	52%
Transgender	0.3 %

#### Sexuality

Lesbian, Gay or Bisexual	7.6%
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#### Marital Status

Single/ never married	55.3%
Short term relationship	0.3%
Married/ co-habiting	26.3%
Divorced/ separated	12.4%
Long term relationship	3.3%
Widowed	2.3%

#### Place of Residence

Own home	34%
Social/ Council housing	16.1%
Renting	27.5%
With parents	12.1%

(n = 287) **Region\*\***

Urban	25%
Rural	55%

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Dublin	19.7%
Leinster (not Dublin)	15.7%
Connaught	30.1%
Munster	31.4%
Ulster	3%

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#### **Other Disabilities**

Blind/ deaf	7.8%
Physical disability	12.7%
Learning disability	7.8%
Other chronic disability	18.6%

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#### **Educational attainment**

Primary	8.6%
Junior Certificate	12.6%
Leaving Certificate	18.4%
Diploma	25.7%
Bachelor	20.1%
Postgraduate	15.1%

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#### **Employment Status**

Sickness Benefit	30.9%
Unemployed/ jobseeker	15.1%
Part-time employment	13.2%
Full-time employment	11.2%
Student/ training	11.8%
Retired/ pensioner	5.9%
Self employed	4.9%
Homemaker	3.3%
Carer	1.6%
Volunteer	1.6%
CE Scheme	0.3%

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<b>Median Income</b>	<b>€11, 960</b>
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#### **Mental Health Care**

##### **Age at first diagnosis 25 years (range= 4 – 60years)**

Admitted to psychiatric hospital	68%
Treated under the Mental Health Act 2001	25.4%
Treated with Medication	85.7%

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(n = 103)	<b>Non medical treatment***</b>	
	Cognitive Behavioral Therapy	27%
	Psychotherapy/ Talk therapy/ Counselling	25%
	Group Therapy	6%
	Vocational Training	5%
	Occupation Therapy	5%
	Addiction/ Alcohol Treatment	4%
	Other (including alternative medicine)	40%
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*	N = 306 unless otherwise stated	
**	Some response do not add to 100% due to missing answers	
***	Adds to more than 100% as participants have multiple answers	

### Recruitment

Anyone over the age of 18 who had experienced and/or was experiencing mental health problems was eligible to participate in the study. People were excluded if they had concurrent organic or degenerative conditions that would interfere with their capacity to give continuous informed consent and/or understand and respond to semi-structured and structured interviews, e.g. late dementia. Participants defined their mental health problems and were not required to have either a diagnosed mental health problem or have received treatment for their mental health problems, nor were those that did precluded from participating.

Recruitment involved a number of strategies, based on snowball sampling and later purposeful sampling. A national advertising campaign was instigated that targeted known groups and places where people with mental health problems might hear of the study. This included the use of community forum links, non governmental organisations, informal networks, organisational web sites and social networking sites, plus national and regional media outlets. Participants were invited to participate in a study about discrimination as experienced by people with mental health problems and received no financial incentive or remuneration.

### Research team

The core research team from Dublin City University (DCU) comprised academics, mental health practitioners and experts by experience, that is individuals who have experience of mental health problems and draw on that experience to advise on policy or research. This research team met regularly with AI to update them on progress and AI advised the research team from a human rights perspective. The research team was also informed by AI's mental health 'Experts by Experience Advisory Group', a group of individuals with experience both of a mental health problem and of advocacy who are advising on AI's mental health campaign.

Seven researchers (the field researchers) were responsible for conducting the majority of structured interviews in the field. Each of the field researchers had personal experience of mental health problems and of working with

other people who had mental health problems in either a support or research capacity. In keeping with the methodology it was important to involve people who had experienced or were experiencing mental health problems in carrying out the research itself. The field researchers underwent an initial two day orientation and training workshop with the rest of the research team at DCU. This was to familiarise themselves with the research methodology and methods, and standardise the researchers' approach to the interviewing process. Thereafter formal group supervision and individual support occurred where any challenges could be resolved through facilitated peer support.

## Research cycles

### Cycle One

The research took place over two interrelated spiraling cycles or phases, with the first both informing the second and providing rich research data on the experiences of discrimination of people with mental health problems. Cycle one consisted of 30 semi-structured interviews where participants were asked to speak in detail about their experience, if any, of discrimination because of mental health problems. It was expected that the information from these interviews would help to refine a more structured questionnaire in cycle two, picking up on contextual nuances of a sample from Ireland.

**Table 2. Profile of Cycle One Participants Only**

<b>Total number</b>	<b>27</b>
Average Age:	43 years (23-62 years)
Sex:	
Men	67 %
Women	33%
Marital Status:	
Single/ never married	48%
Married	33%
Other	19%
Place of Residence:	
Dublin	33%
Galway	4%
Cork	4%
Other	59%

**Employment Status**

Sickness Benefit	30%
Unemployed/ jobseeker	15%
Full-time employment	19%
Student/ training	15%
Other	21%

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**Mental Health Care**

Admitted to psychiatric hospital	56%
ECT	19%
Other treatment	33%

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Only two minor changes to the structured interview were necessary following the first cycle. However, the data from these semi-structured interviews provided rich and important information about people's experiences of discrimination that aided the final analysis of overall findings. Experience from the interviews was also useful for ongoing training and supervision of field researchers. For example, knowledge from cycle one enabled researchers to explore prompts that were more likely to draw out participants on the focus of interviews and to encourage participants to personalise their accounts, rather than speaking in generalities.

The recruitment process meant that most of the 30 participants in cycle one would more than likely be known to the researchers that were interviewing them. There would be an expectation with PAR that people in the community being researched are likely to know each other. This familiarity may have influenced participants to share views that they knew would be in sympathy with the interviewers. For this reason, none of the report's conclusions about the extent or nature of discrimination are drawn solely from cycle one; the report's conclusions are substantiated by both cycle one and cycle two findings.

Semi-structured interviews were digitally audio taped for later transcription. Once recordings were transcribed and stored in encrypted files on a computer the recordings were deleted and the transcribed text anonymised. Transcribed interviews were analysed by a member of the research team experienced in content analysis with the assistance of a software package called N-Vivo. Analysis of semi-structured interviews proceeded with an initial reading of the texts as a whole in order to grasp any trends, patterns or common themes. The interviews followed a loose schedule of questions but in most instances the conversations shifted fluidly from one topic to the next. Transcripts were repeatedly re-read as sub-themes were identified and each line of transcribed text was allocated to a broad category and an associated sub-theme. A list of sub-themes with examples was generated which accounted for all the interviewee said about discrimination.

<sup>9</sup> At the analysis stage two participants' responses were removed from the data set due to incomplete answers. This resulted in a final sample of 304.

## Cycle Two

In cycle two, 306 structured interviews were conducted with people who have or have had mental health problems.<sup>9</sup> They were asked specific questions relating to their reports of discrimination because of mental health problems. This sample included the 30 participants from cycle one who also elected to take part in the structured interviews. In such cases the structured interview was administered directly after the semi-structured interview.

The structured interview schedule was developed in consultation with the full project team and AI's Experts by Experience Advisory group; based on similar studies reported in the literature; and slightly refined during cycle one. The final interview schedule consisted of a battery of four questionnaires.

### Part A

The first section of the interview schedule asked participants for a series of demographics details along with information about their personal history of mental health problems and any treatment or interventions. This section was included in order to determine any correlation between these factors and any individual differences in the reporting of unfair treatment.

### Part B

Experience of discrimination has associated effects on the individual and one of these widely reported in the literature is the relationship between experience of discrimination and people's self esteem. In order to examine this, Part B consisted of the 10 items of the Rosenberg Self Esteem Scale (Rosenberg, 1979). The Rosenberg scale is a validated instrument used as a tool to indicate people's level of self esteem. It has been previously used in research with people who have mental health problems and in previous research studying effects of stigma and discrimination (Berge and Ranney 2005; Link et al., 2001). The intent was to enable an analysis of associations between self-reported experiences of discrimination and self esteem, not to suggest a cause and effect relationship.

### Part C

This part of the interview focused on participants' experience of discrimination using Thornicroft's Discrimination and Stigma Scale (DISC) (Thornicroft et al., 2009) in order to operationalise discrimination. Permission was given by the principal author to use the latest version, DISC 12, as part of the structured interview for this study. Minor modifications were made to the questionnaire based on discussion within the project team. This included an extra question asking participants to identify who in their opinion was responsible for treating them unfairly in any given examples and an extra question in the final section on more positive treatment in health care.

The scale is divided into four sections with each section having a four-point Likert type scale ranging from 'not at all' to 'a lot' and also a 'not applicable' option. The first section comprises 21 questions relating to people's experience of 'being treated unfairly' in a range of life areas including family and other relationships, education, employment, housing, public transport,



social security, religious practice, the criminal justice system and healthcare. The second section includes four questions relating to times when people stopped themselves from doing things they felt were important because of how they thought others might respond to their mental health problems, representing anticipated discrimination. The third section comprised of two questions that related to social distance and coping skills and aims to assess how people overcame discrimination. The last section comprised six questions that asked about times when people were treated more positively because of their mental health problems. Thus the DISC 12 yields four sub-scores for 'unfair treatment'; 'anticipated discrimination'; 'overcoming discrimination' and 'positive treatment'. In addition to responses on the Likert scale, the DISC 12 also asks respondents for a specific example relating to each question.

### **Part D**

Part D comprised of five general questions about discrimination. The first using the same Likert type scale as above asked about the extent that discrimination because of mental health problems has caused distress to participants. The remaining questions relate to sources of support and other reasons why participants thought they may have been discriminated against apart from their mental health problems.

### **Procedure**

Each interview was structured so that the interviewer asked the specific questions and also recorded qualitative responses. There were specific protocols put in place to ensure participants were not unduly distressed. For example, at each section of the interview they were asked if they were experiencing any distress and were happy to continue. Each interview normally lasted between 45 minutes and an hour.

Completed questionnaires were anonymised, inputted to an Excel spreadsheet and quantitative data underwent statistical analysis using SPSS for Windows version 15 and Answer Tree version 3.1. Qualitative experiential data and examples of discrimination underwent thematic analysis, and relevant themes and examples were matched to corresponding quantitative findings for later triangulation and discussion.

### **Pilot**

Both the semi-structured and structured questionnaires were piloted with 10 people who had experience of mental health problems. The number of questions for the semi-structured interviews was reduced following this pilot and no changes were required to the structured interview. However, the length of time for completion of structured interviews was revised at this time and some amendments were made to the protocols for conducting interviews. For example, the initial projected time of 40 minutes for completion was revised to take up to an hour, and guidance for ensuring qualitative responses during structured interview were more focused, were incorporated into interview protocols.



### **Ethical Approach**

Ethical approval for the study was granted by DCU and safeguards were in place throughout the study with specific protocols followed by the research team. Interviews were only carried out by researchers who were thoroughly trained, and who had insider appreciation of mental health issues, thereby increasing their sensitivity to participants. The interviewers selected had experience supporting people with mental health problems and could provide skilled first line support in the event that a participant was to get upset through retelling their experiences. In addition, a list of statutory and voluntary support services was available to participants, specific to each geographic area.

Informed consent is often a contentious issue and in this study, as with any PAR research, consent was seen as an ongoing process (Ramcharan, 2006). Interviewers sought continued consent at designated intervals during interviews, whilst at the same time inquiring into the emotional state of the participant, including when the interview was completed. At the beginning and end of the interview, participants were reminded that they could withdraw their consent to be part of the study at any time until the report was submitted for publication.

No negative distressing experiences were encountered during the course of the study. In fact there were several testimonials from participants who found it beneficial to be able to recount their experiences, which is commensurate with contemporary wisdom on outcomes for participants particularly in qualitative research (Kitzinger 1994; Duncombe and Jessop 2002) and quite often an expected outcome of PAR (Koch and Kralik, 2006).

### Chapter 3: Cycle One Findings

The semi-structured interviews in cycle one were conducted in order to provide an in-depth exploration of people's understanding, experience and the impact of discrimination because of their mental health problems. The findings emerging from this research cycle provide a rich description of these participants' experiences, and provide a personal and experiential context to the quantitative findings in subsequent chapters.

The following results are presented as a summary of the content of the interviews with quotations chosen that best represent the emergent themes. Quotes have had minor edits for legibility, but content and meaning have not been altered. Each quote carries a unique identifier at the end, demonstrating a spread of quotes across interviews. IV denotes 'interview' followed by the interview number. For example, IV2 is a quote from the interview with participant number 2.

#### Participants' reported understanding of discrimination

Participants were initially asked for their understanding of the term discrimination. Most respondents described discrimination as being treated differently from others on the basis of a stereotyped view or erroneous assumption about them, for example:

*Somebody who would be treated differently to someone else because of something different about the person or what somebody sees about the person, it's about perception, not necessarily about something real. [IV1]*

Several people acknowledged that discrimination could be positive, that is conferring some desired benefits or preferential treatment relative to other people.

However, most often people described negative forms of discrimination, likening it to oppression, injustice, marginalisation and disrespectful behaviour based on some characteristic of the individual such as unusual behaviour or simply perceived difference. People acknowledged that there could be many characteristics that might become the basis of discrimination, extending beyond mental health problems, e.g.:

*Well anyone that's treated unfairly – ethnicity, race, colour, gender, traveller status, marital status etc. So it's to be treated unequally. [IV2]*

While most explicit examples of discrimination were highly personal, respondents linked discriminatory practices to the values and norms of society. Discrimination was both being treated differently and often unfairly relative to others in a similar social position on the basis of being perceived as different. Discrimination was also identified as an endemic social problem. Some suggested that discrimination was ubiquitous in Irish society and that there was a long history of classifying people into groups (e.g. religion) and treating groupings differently.

*[Discrimination is] not being treated the same as other people in society, being treated unfairly [IV3]*

Discrimination was perceived to exist in many forms. For example discrimination may be highly subtle or overt, it may vary in terms of impact by being seen as more or less positive or negative, and it may be highly personal or embedded in social structures, institutions or norms. While there were some dramatic and clearly overt examples of discrimination described more often people suggested that discrimination involved subtle and relatively small gestures impacting negatively over time.

*It's kind of hard to measure... because the discrimination has been subtle... ... I try to stop it, you know, and that [has] ended up causing problems... I've lost jobs because of it so... you could say that discrimination has been subtle but it has had large effects. [IV4]*

*Well, I guess there's direct discrimination and there's indirect discrimination, I think, and probably insidious discrimination. You know, kind of covert discrimination and I think, like, you'd know because if you don't get a job and it's because you suffer from depression, it's like direct discrimination isn't it? There's people even going to sue someone because of that. [IV2]*

Discrimination might also be internalised or externalised, that is people recognised they held themselves back from activities, or as some noted, they discriminated against themselves based on an internalised idea of themselves as 'ill'. At times discrimination was located within oneself, whereas on other occasions it was clearly referring to the overt behaviour of others.

*For me, keeping that secret and not talking about it and meeting people socially there's a whole part of your life that you're not talking about. [IV5]*

Respondents described a close relationship between stigma and discrimination and at times the two concepts were not easily separated. People were often acutely aware that being labelled as mad, mentally ill, unstable or even having been hospitalised was considered shameful and this often motivated discriminatory behaviour. Frequently this behaviour was represented in terms of being ostracised, shunned, excluded or mocked.

*Just being shunned, if you like, by my society, where I live... because I behave in a different way. I have problems you know, sometimes I might say to somebody when they ask me what I'm doing, I say I'm doing a bit of voluntary work for mental health and then they're off... [IV1]*

## Examples of discrimination related to mental health

Once the participant's understanding of discrimination had been explored, they were asked to provide examples of areas in their life where they had experienced discrimination. The main items of concern are revealed in the sections that follow.

### Employment

When asked to provide an example of discrimination they had experienced relating to mental health, people most commonly provided examples of what they perceived as discrimination in relation to employment.

Most respondents considered work to be exceptionally important in order to maintain well-being or esteem. For example, some stated that work was a place where they could maintain normality, and have respite from other stressors. Participants described missing out on job opportunities because of mental health problems and often with disregard for their qualifications or work history.

Participants were at times ambivalent about declaring a history of mental health problems on applications for a job.

*...Even going for jobs... filling out forms you're wondering if you should disclose the history that I have... you're hiding yourself all the time. That was a huge source of stress in my life. Now, for the first time in a long time I'm just myself with people. [IV5]*

Suggesting that it is a choice to disclose a mental health problem to a prospective employer oversimplifies the issue. Often people have gaps in their employment history that require explanation.

*I can't get a job, I've tried and tried. And you can get interviews, you fill in the application form, you send it away and you get to an interview and everything is going grand in the interview and there might be a gap in your employment record or whatever. They'll say well where have you been? And I'll say well I was in a psychiatric hospital and you can see the look and it's all downhill afterwards and you never hear from them again. [IV6]*

While some respondents stated that they received understanding and compassion from work colleagues, many also described being shunned, avoided or bullied by others in the work place. Those who were in employment but had faced difficulties and disclosed them to colleagues, managers or human resource personnel sometimes received unhelpful responses or were the victims of pranks because of their mental health problems

*...they're kind of mean jokes and they're not meant in a bad way and I admit that and I know that, but when somebody does something like deliberately put their fan facing you for the whole day and they know you're cold, that's not a joke. Even when you told him not to then that's not a joke. [IV4]*

*I know the head of HR just did not know where to start dealing with me. He was kind of "Oh you have mental health problems and how do we know that you're fixed and how do we know you're not going to break again?" And questions like that where like if I had broken my leg I wouldn't have been asked. [IV7]*

People described how others responded to what they said differently when they were perceived to have mental health problems. Their status as experts in their own fields was undermined. One person for example described how they were well regarded in their field, for their ideas and innovation, and were afforded considerable responsibility and autonomy. When they disclosed they had mental health problems the dynamics with a supervisor changed dramatically.

*...every time I raised an issue saying "well, this needs to change..." it was always being brought back to well, "are you looking at these issues through clear eyes or is it that you're looking at them through your own issues that you're trying to deal with?" [IV7]*

One woman described feeling depressed after being 'bullied' by a co-worker and spending an hour or more each day crying in the bathroom. She opted to resign and on doing so was asked to sign a statement stating that the employer had done all that they could to make the situation work out. However, she stated in the interview that in fact nothing had been offered or done to address the situation or offer her support.

Some people did recognise that there were times that their work performance was impaired to the extent that they needed to take 'time out' from work. Others chose to continue attending working knowing that their performance was impaired.

*I mean, like the first job I ever got I lost it because they said I wasn't able to do the work, I wasn't able to work fast enough and I was making too many mistakes... I would personally put that down to anxiety. I got six honours in my Leaving Cert. I'm not a stupid person. I have a degree now and I'm doing a masters so they can't say I'm stupid. [IV4]*

*Well yeah one problem was that if I was quite depressed I'd still come in because I found that calling in sick sometimes created more problems because ... it was seen as inconsistent. [IV8]*

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The same individual reported suffering taunts and comments that did not help the situation but at the same time they recognised their performance was poor.

*...in the company who I worked for my performance was poor, I suppose the comments were due to that but I suppose they didn't know the reason. My manager came over... asking my understanding*

*of a certain thing and I obviously wasn't showing that understanding because I was depressed that day...as he walked away I heard him say "why doesn't he just leave"... I just wanted to ...make it through the job, but I wasn't in a position to respond that day as such so that kind of annoyed me. [IV8]*

Failure to make accommodation for mental health problems was another problem cited. One respondent reported having obtained higher degrees in three areas but being on a disability allowance for 11 years. Even at the height of the building boom in Ireland he reported not being able to even get an interview for employment in his profession. One problem relating to employment was the lack of accommodation for flexible working hours. He stated that his mental health problems made it impossible for him to sit still in an office for 40 or more hours a week, but flexible working conditions, or part-time work were not available.

### **Financial and other services**

Respondents were aware that disclosure of mental health problems could have a negative impact on their access to financial services. People reported that disclosing mental health problems could have an adverse impact on obtaining bank loans and insurance. People stated that they were not considered a good prospect for a loan.

*I went along in 1999 and I didn't declare the illness and they offered me a mortgage for €350,000 for a house ... and I was farming and I went into them there for €1,000 after coming out of hospital and they wouldn't give me €1,000 because they knew I had a disability. [IV22]*

*...they [the banks] shouldn't write off a person because they have a mental disability, they're just as capable of paying off a bill as anyone else. [IV26]*

Some people had a strong sense that their status as a former mental health patient was used to discriminate against them even when this aspect of their history was not formally disclosed. People from smaller communities recognised that their history of 'mental health service' usage was often widely known and while their status was rarely acknowledged they strongly suspected that this was the basis of discrimination. One man stated he was repeatedly refused private rental accommodation in his hometown despite there being vacancies because he was not welcome.

*It was the community that lived around the house that...I was going to... they didn't want someone going to their area that had a recognised mental health problem. [IV19]*

Some who had experienced prolonged periods of hospitalisation stated that gaps on their curriculum vitae, lack of rental history (and availability

of references), and poor savings histories not only disadvantaged them in terms of applying for employment, loans and private housing, but also served to maintain people within a cycle of dependency.

*Yeah well it could put them into a zone in which they're stuck all their life. They might be on FÁS courses but getting to the next stage and find it very hard to get to the next stage and they could be stuck there... or into the disability system. [IV17]*

Discrimination was reported to limit people's opportunities to participate economically and thus some people become dependent on others. One person described being chastised by family members for remaining dependent on them financially, when also being exceptionally well-qualified but unable to obtain work. In addition to carrying a sense of shame the person also felt insecure, knowing that he could not be supported indefinitely and that his employment prospects were bleak.

### **Mental and physical health care**

It is something of a paradox that respondents often identified particular health professionals as being supportive and immensely helpful in dealing with mental health problems, yet conversely the process of care was also perceived by many to be the source of greatest discrimination. Dealings with the mental health system engendered emotive responses from many participants. A sense of injustice was a dominant theme in the stories of some people who had experienced involuntary treatment, with some suggesting that discrimination began only once contact was made with the mental health system.

*I was after losing everything ... in my business ... and I sort of took to drinking and that was it as well. And I went into hospital and the discrimination started... [IV18]*

People noted that their treatment as psychiatric service users was quite different to their treatment in accessing other forms of healthcare in which one might reasonably expect that choices or options would be put to people and their desires and preferences taken into account.

*...if I was needing general healthcare within a general hospital I would be treated a lot differently...it's just that the conditions within psychiatric institutions in a lot of ways are atrocious. There's no choice of medical interventions, there's one choice... tablets and medicine or ECT... There's no opportunity for psychological or talking therapy if you want to call them that. So that for me would be discrimination. [IV19]*

People expressed that as they assumed the patient role they also relinquished their status as ordinary citizens and were henceforth required to acquiesce to treatment or defer to authority.



*...walk into any hospital... and you'll see countless cases of people who have been discriminated against on a daily basis... in the sense that they don't appear to be treated as first class citizens.... They don't have the same opportunities to... healthcare. They have no opportunities of socialisation with the world outside... [IV19]*

In other health settings, and in common with the experiences of people who disclosed a mental health history to friends, some people felt that health professionals would tend to relate all problems to mental health.

*...my GP... as good as she is...when I would turn up for an appointment, she would ask about my mental health even though it could be a physical ailment. "How's your mood?" would be one of the first questions, because I've a sore throat my mood must be down, you know. [IV20]*

People noted that when they were known to have a mental health problem their motivations, and truthfulness were questioned and respondents reported a sense of being judged.

*As a mother I find that because the doctors know of my mental health issues they're inclined to, even when I'd go with one of the children, they'd be "oh, is she overreacting now, is this her anxiety?" as opposed to, well there may actually be a problem. It's just the sense of judgement I think. You have that hurdle to cross all the time you know before you ever get on to a proper level of conversation, that hurdle has to be jumped the whole time. [IV20]*

### **Being mocked or shunned**

Being the subject of mocking and taunting was an experience that several people reported. This often went back to childhood, inevitably taking a toll on mental health and setting them apart from others:

*I was never physically abused. It was more subtle. Comments made, snide remarks, underhand you know, it wasn't very nice. I've learned to forgive them but it did happen you know, it doesn't always have to be very obvious. [IV10]*

Sometimes people supposed that harm was not intentional, but nevertheless being pointed out as different from peers was seen as confrontational and sometimes damaging. For example,

*I've a tendency to blink quite a lot when I'm stressed and this girl who was sitting next to me in science class, she asked the teacher why do people blink in a certain way right? And of course I had no idea that I did it but as soon as she asked it the whole class turned around and started staring at me, and one girl who was sitting very close to me*



*looks right at me and goes look she's doing it right now. And that's actually when I realised, when I first realised I was doing it. And it was very hurtful...[IV4]*

Verbal 'put downs' also extended beyond childhood and adolescence, and even if construed as good natured humour by some, could be perceived quite differently by the individual concerned and impinge on their well being.

*well with friends and maybe at work... like it was more verbal, put downs or mocking behaviour that I was subjected to, if they're saying that to my face what are they saying behind my back, I was very paranoid and it only increased that... [IV10]*

The isolation that comes from being excluded from relatively minor social interactions was also highlighted.

*I had friends close to me and they knew [that I had been unwell] but they would just ignore me and that made it worse because for instance, they wouldn't ask me to go out for a cigarette with them...[IV24]*

## **Relationships and social life**

### **Interacting with friends and colleagues**

Most participants cited examples of being misunderstood by people and noted that many people did not understand the impact of mental health problems on behaviour. As some people noted, they themselves sometimes did not understand the reasons for their behaviour, but having to account for their behaviour and decisions set them apart from other people. One person described how people were drawn to them when they were elated with bi-polar disorder. At such times they were gregarious, chatty and funny. People (including the person concerned) found it difficult to make sense of changes in mood and presentation:

*I would get very depressed, there would be plateaus when it would be just like this, just sitting here chatting and my friends at the time would come in to the pub and they would expect this high person, this person who was cracking jokes and doing stupid things and if I wasn't doing that, they'd ask "what the f... is wrong with you", what's your problem and they'd walk away. [IV11]*

-31

While many participants described friends as being supportive, several described losing friends as a consequence of being identified as having mental health problems.

*...people I would have bumped into before in say a pub or something like that and you say "Hi I haven't see you for ages" and they say "well yeah" and they just walk away. Basically they've heard stuff about you... There have been many times. [IV12]*

<sup>10</sup> The basic premise behind the face management theory is that all humans have "face" which Goffman (1967) defines as "the positive social value a person effectively claims for himself/herself by the line others assume he/she has taken during a particular contact" (p. 5). Face is considered to be the social image one has of himself/herself based on other's approval and acceptance

Most participants were ambivalent about disclosing a history of mental health service usage to friends or acquaintances. Many reported facing a daily dilemma about whether to disclose or not to disclose reasons why they made particular choices or were behaving in a particular way. Participants revealed elaborate 'face management'<sup>10</sup> strategies so as not to expose themselves as vulnerable or unwell.

*... you couldn't really say "I'm on really heavy medication for depression at the minute and that's probably why I'm putting the weight on" and so you're having to keep secrets all the time...there's an awful lot going on up here [your head] that needs sorting out and if you're having to keep secrets ...and come up with excuses as to why you're having to behave in such a way because you don't want it out in the public domain... [IV7]*

*...I don't drink because with my mental health problem... medication and stuff like that and that's been the case...since I was 18 so I kind of stayed away from it as much as possible. I found especially in college, it always comes up the question, "oh why aren't you drinking". I suppose it's a case of answering the question but not answering, you're not giving the full answer but not being rude... [IV8]*

To some extent face management strategies were successful and some people stated that few friends, acquaintances or indeed family members were aware of their problems. Others described making careful considered choices about who they would share such information with.

*I wouldn't tell them, at all. Unless I had to or something like that... but with friends, close friends they'd be kind of even closer to me because I'd be more open with them but there'd definitely be a difference in like they'd just be more conscientious if I do something, they'd just be 'ah that's because you have whatever'. [IV13]*

### **Relationship with family and partners**

One young male noted that it was difficult to maintain intimate relationships as a consequence of being labelled as having mental health problems. Disclosure of a mental health problem was also frequently reported to change the dynamics in relationships.

-32

*Yes sometimes, in the case of ex-boyfriends... They'd pull away because they'd be just kind of thinking I can't have a future with this type of person. [IV13]*

*... they wouldn't be as keen on you or as interested in you and there would be a social phobia about it from women if you declare mental illness because before when I had a girlfriend I went into hospital and she just left me and that was it. [IV14]*

*...I had a boyfriend... [When] I told them they'd kind of freak out or couldn't deal with it. It would make them more cautious toward what they said to me, and how they reacted to things yeah, it definitely made a difference. [IV13]*

In another case one father had access to his children restricted when he was hospitalised, which he suggested was not only traumatic for him but was unfair on his children.

Some people likened the change in the relationships with families to being 'looked after' or people suddenly acting like they were 'treading on egg shells' around them.

*...they just kind of step back and they'd be like oh and they think more about what they're going to say to me and how I'm going to react and just you'd be treated differently basically. [IV15]*

Others described having their status undermined in their family whereby their opinions were no longer valued or were dismissed after they had been diagnosed with a mental health problem. For example, one person who was the victim of an incestuous relationship was labelled as emotional and unstable as a child and later diagnosed with a mental health problem. Being labelled this way was perceived by the respondent as a means to silence her.

*I had to be silenced in some way, mental... instability had to be the way of dealing with it because how else could they shut me up? So everything I said was irrelevant, over emotional, over sensitive, mountains out of mole hills and that was when my mother wasn't calling me a slut and a whore and things like that... my brother and my sisters picked up on the mental instability bit but they had no idea of the source of it... everybody had me labelled as mentally unwell and there was no valid reason for it but my siblings didn't know that... [IV16]*

### **The impact of discrimination**

A few respondents stated that discrimination relating to mental health was insignificant for them as they were successful in concealing their history or any manifestation of mental health problems. Indeed active concealment of a mental health history or careful face management so as not to reveal evidence of mental health problems was common to all respondents at least some of the time. Some chose to move within a circle of supportive friends and acquaintances or avoided situations in which they anticipated that discrimination might be encountered. This had the result of limiting some peoples' lives and social networks.

Several people described how they were angered by discrimination and injustice and this had positive effects in terms of motivating them to do something about discrimination. Some, for example, made a point of being

quite open about their histories, or using discrimination to 'drive them on', prove people wrong in their assumptions, motivating them to succeed.

More often however, the effects were negative and people described how they felt hurt, stressed or tainted, and how their self-esteem and confidence were eroded by experiences of discrimination. As has already been noted, discrimination can radically limit people's opportunities in important areas of life. Participants also described being socially isolated.

*...it can isolate you, it can stigmatise you, you don't feel part of the community, you're on the outside. [People are] afraid of the person who has the mental illness... that they will attack them, but that's the fear and people with mental illness are... afraid that others are going to attack them. [IV23]*

People said that discrimination caused the severing or weakening of connections with other people. Participants internalised the negative messages about themselves, which inhibited them further from realising opportunities and developing helpful relationships. The impact of this isolation and loneliness was captured profoundly.

*It's horrible, it's awful, it makes you feel like you're the loneliest person in the world, the only person in the world that has a problem or that is experiencing some difficulties. [IV24]*

*It can be very hurtful, I've been hurt by it. And I work with service users and I have friends who are service users. And I see them almost afraid at times to move forward because they're afraid of the judgment and of people. The illness is frightening enough without the added pressure. [IV25]*

As negative messages become internalised people become primed to see themselves as inadequate in some way and to expect a degree of discrimination from others. People described taking on the role of being different from others.

*... I suppose in some sense it continues that sort of lifestyle where you're on the margins, where you don't feel accepted, where you actually... feel inhibited... taking part in social intercourse... because you don't think you'll be accepted... you begin to actually believe that you're different as well... it also makes you feel not very good about yourself, your self-esteem, hope for the future. [IV9]*

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People used the term 'self-discrimination' unprompted to describe how they were inhibited from sharing aspects about themselves or putting themselves in situations that they predicted would lead to discrimination.

*Well it's just that... it's the stigma... you end up almost self discriminating to try and avoid the stigma... you won't put yourself in situations*

*because you know that it'll come out and you're one step away from being shunned by friends, by colleagues... I think you become your own worst enemy... you start to perceive a certain amount of discrimination and ... you react to it... well I won't do such and such because they'll say whatever... [IV7]*

*...I suppose with mental health you kind of protect yourself really and let as few people know so I suppose that's discrimination against yourself in a way. [IV24]*

*...you start to discriminate against yourself and it becomes very difficult to reintegrate back into that 'yes I am somebody of value' and 'I have just as much a right to be in this queue for this concert as the person in front of me' or 'I've just as much a right to demand such and such as the next person', because for me that was the biggest issue... the self-esteem. [IV7]*

When people's credibility is repeatedly questioned or their opinions marginalised or dismissed this can have destructive consequences on confidence and self-esteem. One individual described how their view of the self as incapable, invalid or untrustworthy can become internalised by the individual and shared among family, friends and professionals.

*Other people set limitations according to what my mental ability was or mental capabilities were, that limited me and I limited myself because of my influencing family... who instigated it.... It was soul destroying, soul destroying. You don't exist you know. [IV16]*

### **Addressing discrimination**

Participants were asked for their thoughts on how discrimination could be tackled in Irish society. Some participants did not perceive that it would ever be possible to fully eradicate discrimination but gave suggestions for ways in which prejudicial attitudes and behaviours could be challenged and discrimination reduced.

### **In education and media**

Education, particularly commencing early in life, was considered by most people to be the most useful intervention to reduce stigma, increase public understanding and reduce discrimination.

-35

*...it really needs to be brought in right from the beginning, because children wherever they're getting it from - their parents, their friends, their neighbours - they've no respect for other people. They've no idea, the things that they say to each other, they've no idea how hurtful they can be, and that's one of the main things for the long term. I guess they could do the same thing in workplaces ...know if you just have a little bit of respect for other people it can make it such a nicer place to work. [IV4]*

Some recommended incorporating messages about positive representations of people with mental health problems, the impact of discrimination on people, and demonstrating that it is okay to be vulnerable.

*... just make them aware that it's nothing to be ashamed of. You know it can happen to anyone, there is no shame in mental health issues, there's no shame but some people make it out to be a shameful issue. [IV18]*

Participants noted that any education needed to be carefully constructed so as not to reinforce stereotypes.

*The main thing we need is education about mental illness especially in our schools and colleges, like people with mental illness just shown in a positive light. There's a lot of people with a mental illness who have done great things, who are doing great work, show the good sides, we always see the bad sides, we always hear in the news like 'mad man' did this or that but we never hear of all the good things people do so promoting positive mental health, promoting people who are doing well. [IV27]*

Emphasising community development, community cohesion and collective responsibility for the well-being of the members of the community was emphasised by some. Some also recommended more community and society wide media campaigns addressing discrimination relating to mental health directly and informing people of the harm that it could cause. In parallel some suggested that there needed to be greater sensitivity to mental health matters by media outlets, advertisers and producers.

*I actually made a complaint against an advertisement that was on the radio, it was an advertisement for KitKat nutty [the ad mocked people with mental illness]. Things like that should be stopped. I found that offensive especially for someone with schizophrenia or hearing voices but hearing that on a radio can be very distressing. [IV28]*

### **Changing our view of mental health**

Some people argued strongly that the very way mental health was viewed, primarily according to a medical model, in itself contributed to discrimination. Some people suggested that the language or labels used by government departments could often perpetuate helplessness and lowered people's self esteem. For example using terms such as 'lone parents' marginalised parents who were not married in the same way as the language of illness implied a particular view of people with mental health problems. Several people spoke of changing the language and emphasis towards promotion of well-being and prevention of mental health problems. For them more education about 'mental illness' might be counterproductive.



*I'd actually like to see them tackling the whole concept of the medical model, I'd like to see them taking some sort of national enquiry [into] the effects of modern day mental health services to the people that use them. [IV19]*

One person suggested that a purely medical model prevented people from exploring and addressing the causes of mental health problems. This participant suggested that education (as advocated by others above) had failed because by promoting a medical model people were seen to have faulty genes or biology, reinforcing the idea of difference. The participant went on to suggest that sharing stories of breakdown, restoration and recovery as well as engaging in debate about mental health problems might help tackle discrimination.

*...if we're to tackle stigma we have to hear people's stories of how they ended up with a mental health problem in the first place or how society has contributed towards that, and how society can actually try and alleviate that challenge in itself. So the government needs to change its tactics I suppose in some sense to tackle stigma. Yes education... but educating people through people's life stories etc. and not through educating them through an illness model or anything like that. And I believe we need a public debate about this not some kind of media thing whereby we're just telling people, we need to engage in debate, dialogue and the Government needs to get out there and actually challenge people and put them straight, but they also need to get behind the [service user] movement in some sense and join them and force formative action... [IV9]*

### **Perspectives on legislation and discrimination**

Mental health problems fall within the definition of disability as one of the nine grounds for which discrimination is prohibited under Irish equality legislation. In spite of this, some respondents felt that regulation in relation to discrimination and mental health was inadequate or insufficiently robust to afford people protections. Some participants recommended specific legislation to address the circumstances of people with mental health problems, though this may also reflect a lack of knowledge of the scope of existing legislation.

*If I was to say something racist or discriminatory around someone's religion they could actually take action against me in a court. It doesn't seem to apply to people with mental health difficulties ...I would like to see the Government put some sort of legislation in place that gives the same sort of protection or equality to people who have used or use mental health services or who have had a mental health diagnosis. Some sort of specific legislation I suppose, sort of give people some sort of safety. [IV6]*

For others some it was a question of the proper enforcement of existing laws.

*They [the Government] already have it there but they don't enforce it, they [say] a certain population of your workforce has to have a disability I think it's three or four per cent, it's fairly high and they're not enforcing that, even in their own government offices, they don't have that level of people working for them, it's highly unfair when they're not enforcing them even for themselves. [IV26]*

However, several respondents were pessimistic about the potential for government agencies to counter discrimination in important areas of life such as employment. At a time of high levels of unemployment, one participant noted that employers would employ those they saw as most capable of doing the job and benefiting them most, leaving those with mental health problems or indeed with any kinds of disabilities likely to be excluded. Some questioned the utility of legislation outright, acknowledging, for instance, that for those people who had spent lengthy periods of time in hospital or for whom mental health service use had come to define them, legislation could not offer protection in every aspect of their lives.

*...some of the people who I would have worked with in my last job, kind of well [being a psychiatric service user] very much defines who they are. For somebody who...it's taken over their whole life ... how do you legislate to ensure that they don't get discriminated against? I'm not sure how you'd do it. [IV7]*



## Summary

- The qualitative interviewees were ready, willing and able to talk about the experience of prejudiced attitudes and discriminatory behaviour they had encountered, indicating discrimination had a widespread presence and a significant meaning in their lives.
- Participants gave thoughtful descriptions of the nature of discrimination, describing it as being treated negatively and/or unfairly on the basis of perceived differences linked to societal ideas of what is 'normal'.
- Discrimination was seen as a complex phenomenon, operating at many levels and affecting their lives both in subtle and more obvious ways. Overt discrimination could consist of multiple small incidents of teasing, mocking, or cruelty that had a cumulative effect. Covert discrimination was sometimes hidden because of non-transparent systems, for example, the lack of a need to give comprehensive reasons for being turned down in relation to financial or employment decisions.
- Many sites were identified where participants perceived they had experienced discrimination, for example, health care systems, community, family and other relationships, financial institutions and employment.
- Participants identified a process of 'self-discrimination', a term that was used unprompted. This consisted of internalising societal understandings of mental health that undermined self-confidence and self-esteem and caused participants to withdraw or limit themselves in social setting and in striving for life opportunities.
- Interviewees reported a large personal impact both on their sense of self and on their place in the world, including personal, interpersonal and more general social status. Feelings of disempowerment were pronounced particularly in being negatively evaluated in relation to their judgement making capacity and credibility. They felt obliged to use 'face management' techniques, and were consciously making decisions about disclosure.
- Interviewees suggested that there should be positive portrayals of people with mental health issues in the public and that there was a need to highlight the impact of discrimination.
- The view was expressed that there is a need to reconceptualise our view of mental health, particularly combating an overly medical approach because this was seen to contribute to discrimination by presenting people with mental health problems as different.

## Chapter 4: Cycle 2 findings

<sup>11</sup> For each participant, analysis of responses to the structured interviews yielded five sub-scores. These scores were for self esteem and the four sub-scores of the DISC 12: 'unfair treatment'; 'anticipated discrimination'; 'overcoming discrimination' and 'positive treatment'. Mean scores were calculated for each of these and the relationships between them examined. A mean score was calculated using a binary score for each item, for example, in the unfair treatment sub-scale, a score of zero indicates no unfair treatment and one indicates a report of some level unfair treatment. The mean score for overall experienced unfair treatment is then calculated as the percentage of items in which unfair treatment is reported. Scores for other scales were calculated similarly.

This section provides findings from the structured interviews conducted. Due to flaws in the data from two questionnaires only 304 of 306 interviews could be used for quantitative data analysis. The structured interviews provide both quantitative and qualitative findings. Illustrative examples of verbatim quotes are reported alongside quantitative findings to give contextual substance to emerging quantitative findings. Highlevel findings are presented initially, followed by more detailed examination of each of the sub-scales of the questionnaire.

All statistical analysis was carried out using SPSS for Windows version 15 and AnswerTree version 3.1. Descriptive statistics were determined by analysis using SPSS for Windows. Further data mining was then carried out with AnswerTree using the CHAID routine in order to establish any significant associations between unfair treatment and demographic details or personal history of mental health care. AnswerTree splits the data into groups based on the percentage of that group reporting unfair treatment with each subgroup significantly different from other groups on the same level. Within an individual test CHAID automatically adjusts the probability for the number of comparisons to reduce the number of erroneous significant findings. In all cases, all observed significant findings are reported.

### High Level Findings

In all, 95.4 per cent (n=292) of participants reported some level of unfair treatment as a result of a mental health problem. The number of participants reporting no unfair treatment (n=14) was too small to determine any significant salient features of the group.

On average participants reported unfair treatment in 41 per cent of the 21 items<sup>11</sup> of the unfair treatment scale. Another way of viewing this is that participants experienced unfair treatment across 41 per cent of applicable areas of their life.

This score was used to examine the relationship between self-esteem and reported experiences of unfair treatment. Self-esteem was negatively correlated with unfair treatment (p=0.021). This means that those with higher self-esteem tended to report experiencing less unfair treatment.

### Unfair Treatment

In this section participants' experience of being treated unfairly because of their mental health problems are examined in greater detail. Participants were asked 21 questions (Section 1 of the DISC 12) relating to their experience of being unfairly treated and asked to give examples. Figure 1 illustrates the percentage of people who felt they had been treated unfairly and the extent of reported unfair treatment according to each question.

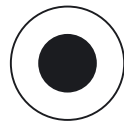
Results for each item of the unfair treatment sub-scale of the DISC 12 are then presented. For each item, the overall level of reported unfair treatment is given by combining all responses that indicated 'a little', 'moderate' or 'a lot' of unfair treatment. Illustrative quotes are also provided. Any factors that were found to be significantly associated with the level of reported unfair

treatment are listed. A short discussion provides some context for the levels and associations observed.

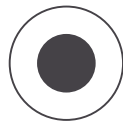
**Figure 1. Percentage of participants reporting unfair treatment for each question**

N= number of respondents

Key to graph



A lot



Moderately



A little



Not at all

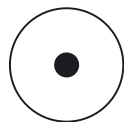


Total affected

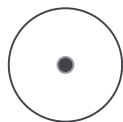
**Have you been treated unfairly because of mental health problems:**

N= 299

in making or keeping friends?



19.1%



14%



31.1%



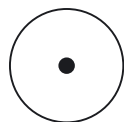
35.8%



64.2%

N= 288

by the people in your neighbourhood?



12.8%



10.8%



16.7%



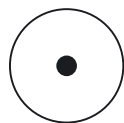
59.7%



40.3%

N= 266

in dating or intimate relationships?



16.5%



10.9%



15%

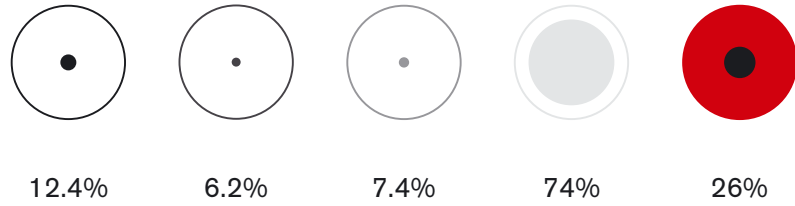


57.5%

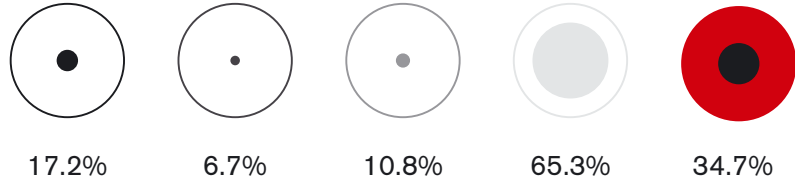


42.4%

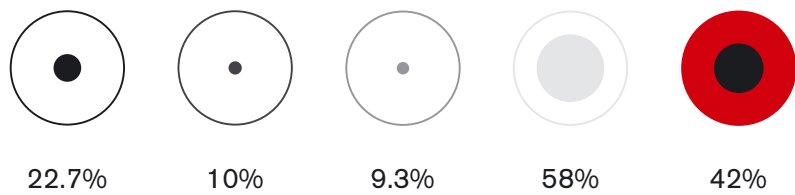
N= 242 in housing?



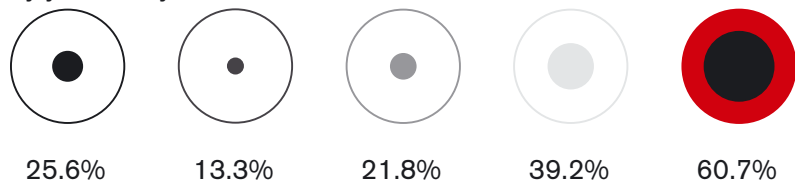
N= 268 in your education?



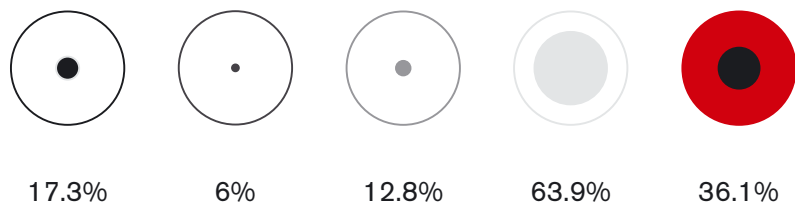
N= 150 in marriage or divorce?



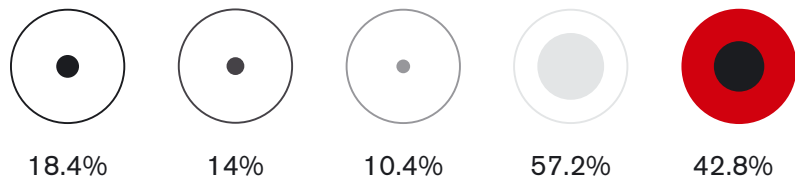
N= 293 by your family?



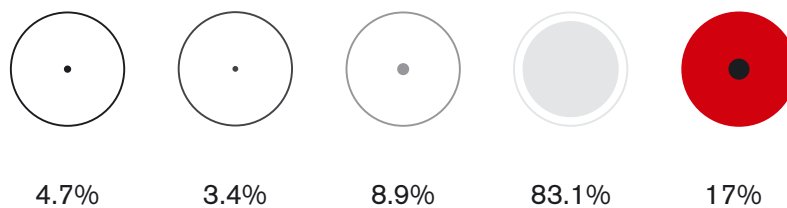
N= 266 in finding a job?



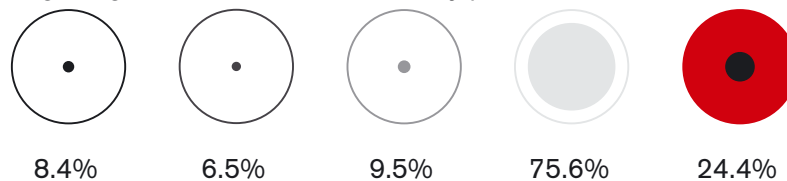
N= 250 in keeping a job?



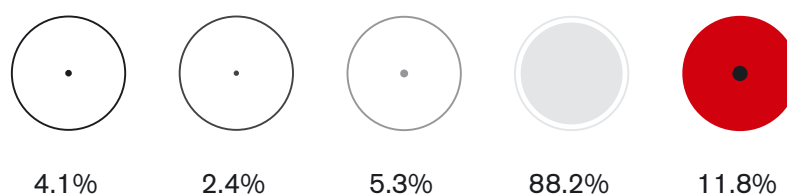
N= 236 when using public transport?



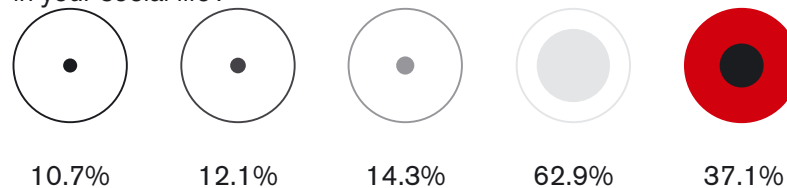
N= 262 in getting welfare benefits or disability pensions?



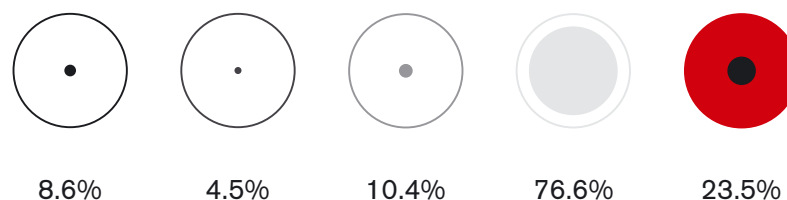
N= 245 in your religious practices?



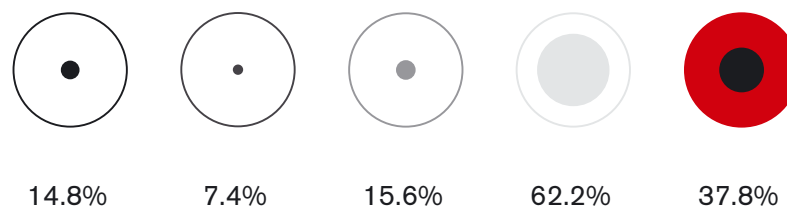
N= 280 in your social life?



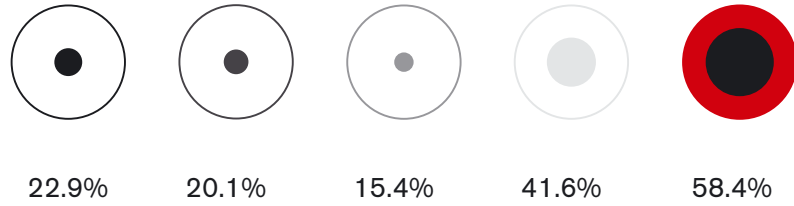
N= 222 by the police?



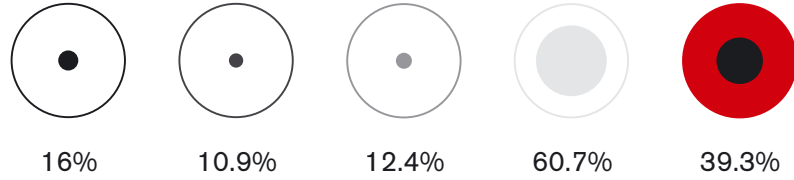
N= 270 when getting help for physical health problems?



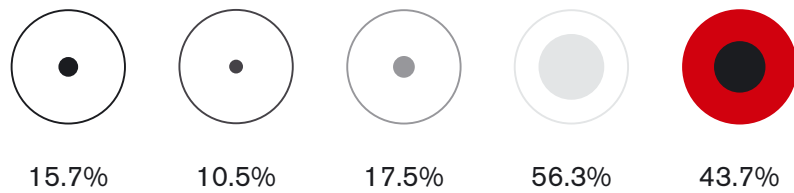
N= 279 by mental health staff?



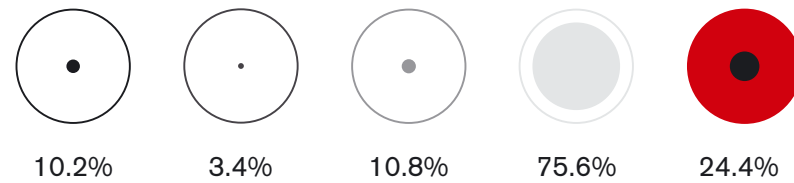
N= 275 in your levels of privacy?



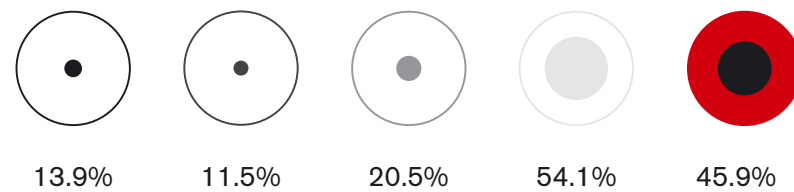
N= 286 in your personal safety and security?



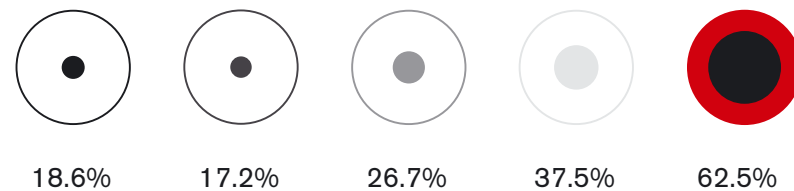
N= 176 in starting a family or having children?



N= 184 in your role as a parent to your children?



N= 285 avoided or shunned by people who know that you have a mental health problem?



<sup>12</sup> Medicine side - effect tablets are often prescribed to counteract side-effects that people are having from taking anti-psychotic medication.

### Item 1: Have you been treated unfairly in making or keeping friends?

This was the area where the highest percentage of the participants in the study felt that they had been unfairly treated. Nearly two thirds (64 per cent) of the people in the sample [192 /299] reported unfair treatment in making or keeping friends.

*Initially no one wanted to know, I was marginalized from the group. No one would ask how you were. Written off would be the term I would use.*

*When a friend heard I was on anti-depression tablets she treated me unfairly, she ended the friendship. In her opinion anyone on antidepressants wasn't a strong person.*

Several factors were associated with higher reports of unfair treatment on this item. A much higher proportion of those who were prescribed medicine side-effect tablets<sup>12</sup> (80 per cent [56/70]) felt unfairly treated in making or keeping friends than those who were not on such tablets (59 per cent [136/229]) ( $p=0.002$ ).

Admission to hospital was also significantly associated ( $p=0.005$ ) with being treated unfairly in making or keeping friends with 70 per cent [140/199] of those who had been admitted to hospital reporting unfair treatment compared to 52 per cent [52/100] of those who had never been admitted to hospital.

*Some people who judged me as being in the mad house even though they probably had undiagnosed issues themselves. If you had been in prison for any period you would have paid your debt to society. It would be considered very discriminatory to refer to [your] past.*

Age was also significantly associated ( $p=0.013$ ) with being treated unfairly with a high proportion (79 per cent [45/57]) of those aged 33 and under and those aged 44-49 (77 per cent [48/62] reporting being treated unfairly in making or keeping friends. Those aged 34-43 were less likely to report being treated unfairly (62 per cent [56/91]). Those aged over 49 had the lowest level of reporting of being unfairly treated (48 per cent [43/89]).

These findings are concurrent with the literature on the desire for social distance from people with mental health problems and the reduced size of friend networks for people with mental health problems (Angermeyer and Matschinger, 2003; Dietrich et al., 2004; Lauber et al., 2004; Thornicroft, 2006). Interestingly these results suggest, for this group, that this social isolation is increased for those with a history of hospitalisation or who have been prescribed side-effect tablets. It also shows that unfair treatment is not equivalent across age groups. Again, this is supported by literature on attitudes that have shown that age plays a role in the way the general public view mental health (e.g., NDA, 2007).



## **Item 2: Have you been treated unfairly by the people in your neighbourhood?**

Forty per cent [116/288] of the people who replied to this question reported having been treated unfairly by the people in their neighbourhood.

*Some local retailers, shopkeepers, neighbours interacted differently towards me, subtly and directly.*

*[A] neighbour tells people to keep their children away from me. She talks about me negatively at residents meetings and to the community Garda.*

*Some that would have known [about my mental health problem] would avoid me like it's contagious.*

Results demonstrated a variety of significant associations between unfair treatment by neighbours and factors relating to treatment history. Admission to hospital was significantly associated ( $p < 0.000$ ) with being treated unfairly by the people in their neighbourhood. Nearly half (48 per cent [93/193]) of those who had been admitted to hospital reported unfair treatment compared to 24 per cent [23/95] of those who had never been admitted to hospital. The number of admissions ( $p < 0.000$ ) and length of stay ( $p = 0.001$ ) were also positively correlated with reports of unfair treatment. Those more frequently admitted to hospital and for longer periods reported greater unfair treatment by neighbours. Positive correlations were also found for those prescribed medicine side-effect tablets or mood stabilisers (both  $p < 0.000$ ) with both groups more likely to report unfair treatment on this item.

International literature has recognised a persistent sense of threat among many communities at the prospect of patients from psychiatric hospitals living 'among them' in community residences. This is best exemplified in the frequent 'NIMBY' (not in my backyard) campaigns against community-based mental health residences that have been documented (e.g., Sayce, 2000). Something similar, although less formal, appears to be occurring in the findings from the current study. Respondents commonly reported exclusion, isolation and harassment in their communities, which they attributed to their mental health problems. The National Economic and Social Forum (2007) cited evidence that Irish people still regarded the provision of community services with caution due to a fear of threat for their safety, while 36 per cent of people in the recent See Change (2010) public attitudes survey said they would be uncomfortable living next door to someone with a diagnosis of schizophrenia. Similarly, these results are also consistent with Irish evidence that less than half of the general public would be comfortable having people with mental health problems living in their neighbourhood (NDA 2007). We can see the possible impact of these negative attitudes in the reported experience of participants in this study. At least in some Irish communities and neighbourhoods these attitudes appear to be manifesting as unfair treatment against people with mental health problem, and those with a history of hospitalisation are particularly impacted by this treatment.

### **Item 3: Have you been treated unfairly in dating or intimate relationships?**

Forty two per cent [113/266] of participants reported having been treated unfairly in dating or intimate relationships.

*I was in a relationship for three months I told her about my illness and two days later she texted me and broke it off.*

A lower proportion ( $p=0.005$ ) of those who were married, cohabiting, or in a short-term relationship felt that they had been unfairly treated (22 per cent [15/68]) than those in other types of relationships (49 per cent [98/198]).

There was also a significant effect ( $p=0.027$ ) of being prescribed medication with 62 per cent [23/37] of those who had been prescribed medication reporting being treated unfairly in dating or intimate relationships compared to 39 per cent [90/229] of those who had been not been prescribed medication.

*My fiancé called off my wedding because I told him I was on antidepressants.*

*People don't know how to respond to me if my hands/legs are shaking because of medication, they are afraid of it, don't understand.*

The findings of this item show that many participants in this study felt that having a mental health problem impinged on their capacity to form positive and lasting intimate relationships. Unfair treatment was reported less in newer relationships, perhaps where the issue of mental health had not yet arisen. However, not enough evidence was available to make firm conclusions about how having a mental health problem can determine how one is treated in different types of relationships.

### **Item 4: Have you been treated unfairly in housing?**

Just over a quarter (26 per cent [63/242]) of those who answered this question reported having been treated unfairly in housing.

*I was unable to be named on a house insurance policy because I was being treated for a mental health problem.*

No associations for medical history were found for this item but a much lower percentage (five per cent [4/77]) of those living in their own homes, flat, private rental room or local authority housing had a perception that they had been treated unfairly in housing compared to other groups (36 per cent [59/165]) such as those living with parents or in hostels or group homes.

This could suggest that unfair treatment occurs primarily at a stage where people with mental health problems are trying to obtain housing and are

undertaking the necessary procedures to ensure tenancy or ownership. However further research would be required in order to determine the causes of perceived unfair treatment in housing for those who experienced it. Evidence from other jurisdictions indicates that even where housing is secured by people with mental health problems, it tends to be of lower quality and with less secure tenure (Social Exclusion Unit, 2004). This finding is important because secure, appropriate housing is both a determinant of mental health and a factor influencing recovery from a mental health problem (WHO, 2004).

#### **Item 5: Have you been treated unfairly in your education?**

More than a third (35 per cent [93/268]) of those who answered this question reported having been treated unfairly in their education.

*Failure of college tutors to acknowledge or understand the impact SSRI medication was having on my writing and concentration.*

*Vocational training. Other people were put in for exams and I wasn't. I thought that I should at least have been given the opportunity to fail. I should have been asked.*

Again, age was found to be associated with the perception of unfair treatment, with 61 per cent (17/28) of participants aged 29 or under saying they had been treated unfairly in education compared to 32 per cent (76/240) of those over 29 years of age ( $p=0.020$ ).

The high level of reported unfair treatment in education is concerning particularly given the vital role of education in enabling people to participate meaningfully in society. The age discrepancies may be accounted for by higher educational expectations of younger generations, or a greater sense of the importance or relevance of education at this life stage. However, it does not necessarily follow from this evidence that unfair treatment in education ceases to be a problem as you get older. It was not possible to ascertain more precisely in what areas of education, and from whom, unfair treatment was reportedly experienced, this area would warrant further research.

#### **Item 6: Have you been treated unfairly in marriage or divorce?**

Forty two per cent [63/150] of those who answered this question reported having been treated unfairly in marriage or divorce.

*My wife. Her view would be that she would criticise me all the time unjustly. She would call my judgement into question.*

*[I was] very badly treated because of my mental health, he had no knowledge of all that was happening, he didn't want to know. I now was changed from being a capable person to a crying person and he didn't want to know.*

*She is totally denying me access to my son for the last three years. She is demanding intimate medical details before she will allow access to my son.*

There was a significant effect ( $p < 0.0001$ ) of marital status on whether people felt that they had been treated unfairly in marriage or divorce. A much lower percentage of those who were married/ cohabiting, single, never married or widowed (27 per cent [29/108]) had a perception that they had been treated unfairly in marriage or divorce than those who were divorced or separated or in long term or short term relationships (81 per cent [34/42]).

There was also a significant effect of being prescribed medicine side-effect tablets ( $p = 0.0261$ ) with a large percentage of those prescribed medicine side-effect tablets (61 per cent [17/28]) feeling they had been treated unfairly in marriage or divorce compared to a lower percentage (38 per cent [46/122]) of those not prescribed side-effect tablets.

Although findings for Item 3 above showed lower reports of unfair treatment for those married or cohabiting, nonetheless a large number of participants perceived that they had been unfairly treated by partners. This is consistent with measures of duration and quality of marriages for people with mental health problems elsewhere (Zlotnick et al., 2000; Kessler et al., 1998). The findings do not sufficiently separate different forms of partnerships to be able to draw conclusions as to when people with mental health problems are more or less likely to feel unfairly treated.

### **Item 7: Have you been treated unfairly by your family?**

More than three in five (61 per cent [178/293]) of those who answered this question reported having been unfairly treated by their family.

*My sister and brother said "stop this nonsense", said I was attention seeking, they didn't understand at all. My mother could say cruel things too, told me to get on with it.*

*When I had a dispute with my mother she asked if this was part of my condition and the actual issue was swept aside.*

Again there were a series of significant associations between medical history and the perception of unfair treatment by family. Being prescribed mood stabilisers ( $p = 0.001$ ), anti-psychotics and side-effect tablets, as well as length of stay in hospital ( $p = 0.022$ ) were all related to higher reports of unfair treatment.

*My family won't listen to me because I was in [hospital] and on tablets. They think I'm not normal.*

These are interesting and difficult findings. Families are seen as important sources of support, often the main social contact for people with mental health

problems outside of contacts in services (e.g. Bates, cited in Sayce, 2000). Yet almost two thirds of participants in this study perceive their treatment by their family as unfair at times. In one sense this is not surprising, as families are influenced by the same social norms as the wider population that give rise to stereotypes and prejudices about mental health problems. Moreover, as some of the qualitative quotes illustrate, family members' behaviour may be based on misunderstanding or motivated by genuine concern that may manifest as paternalism. Nonetheless, from the perspective of the participants in this study, and as reported elsewhere (Peterson et al., 2007; Thornicroft et al., 2009; Read and Baker, 1996) familial relationships are perceived as a common site in which unfair treatment is experienced. Given this consistent finding, it is an issue that is in need of some attention.

### **Item 8: Have you been treated unfairly in finding a job?**

More than a third (36 per cent [96/266]) of those who answered this question reported having been treated unfairly in finding a job.

*I did an interview which went very well and I got the job. I was asked what was the nature of my disability and when I told her it was schizophrenia she never got in touch with me after that.*

*I was told when I applied for my job as a teacher that the stress would kill me because I had been mentally ill.*

Being prescribed certain medications was associated with higher reports of unfair treatment. There were significant positive correlations between unfair treatment and being prescribed side-effect tablets ( $p < 0.000$ ) and anti-psychotic tablets ( $p = 0.001$ ).

*At an interview for a job I was told I was psychotic and would I hurt someone. Even though I was well and it was none of his business.*

Admission to hospital was significantly positively correlated ( $p = 0.002$ ) with having been treated unfairly in finding a job, as was length of stay ( $p < 0.000$ ) and involuntary treatment under the Mental Health Act (2001) ( $p = 0.003$ ).

There is a similar pattern here to previous findings where being prescribed side-effect and anti-psychotic medication as well as being hospitalised is positively correlated with reported unfair treatment. However, it is not clear if these factors were always disclosed while seeking a job, whereas we may assume this knowledge in interactions with family for instance. However, as in Peterson et al. (2007) some of the qualitative quotes do provide corroboration for the existence of clear instances of unfair treatment and, in some instances recounted above, appear to amount to clear breaches of the Employment Equality Acts. It is also possible that the greater incidence of unfair treatment for those having been admitted to hospital results from having to account for gaps in their employment history and therefore a greater

difficulty in concealing a history of mental health problems. This was certainly evident in the cycle one findings. Those who have experienced mental health problems but not hospitalisation may be able to maintain some level of employment while unwell, whereas this is not an option for those admitted to hospital. Similarly people on side-effect or anti-psychotic medication may have mental health problems that are more apparent, and thus less easy to disguise than others. This would require further investigation to draw firmer conclusions on the impact of hospitalisation on employment prospects.

### **Item 9: Have you been treated unfairly in keeping a job?**

Forty three per cent [107/250] of those who answered this question reported having been treated unfairly in keeping a job.

*After divulging at interview stage about my mental health problems it was always an issue during my work placement. My supervisor told me my personal issues had to be kept separate from my work and that they were not there to support me. [I] felt very exposed.*

*Staff found out I was bi-polar and started to ignore me and to call me retard and rehab man. I complained to the manager, nothing was done. I left after that.*

There was a significant association with both having been prescribed anti-anxiety drugs ( $p=0.025$ ) and mood stabilisers ( $p=0.024$ ). In both cases these prescriptions were associated with high reports of unfair treatment in keeping a job.

*As soon as they found out I was on medication I was suspended. I was working in a factory. I lost my job because of it.*

Unfair treatment because of a mental health problem caused many participants in this study difficulty in maintaining employment, and in some case they perceived it as the reason for losing their job. The associations with medication need careful attention in this instance. On the face of it, the fact that a job applicant or employee is on medication is not a valid reason for not offering him or her a position or for terminating employment. However there may be individual cases where, for example, the side-effects of certain medications might affect the person's capacity or competence to do the job in question, in which case what might be perceived as unfair treatment would not amount to discrimination as the treatment is based on justifiable grounds. It is interesting to note that hospitalisation ceases to be a significant factor in reporting unfair treatment in keeping a job, supporting the assumption made previously that history of hospitalisation is a barrier at the point of entering work.



### **Item 10: Have you been treated unfairly when using public transport?**

Seventeen per cent [39/235] of those who answered this question reported having been treated unfairly when using public transport.

*A driver took my pass off me. He said I had to prove I was on disability.  
A nurse had to get it back for me.*

*One bus driver demanded of me twice "how come I had a bus pass?"  
and I had to give him details of why I had been in hospital and how  
long. The alternative was to pay or not to get the bus.*

Being prescribed medicine side-effect tablets ( $p=0.002$ ), anti-anxiety drugs ( $p=0.038$ ) and length of stay in hospital ( $p<0.000$ ) were all positively correlated with higher reports of unfair treatment on this item. There was also an effect for employment status ( $p=0.013$ ), with students or those in training, people on sickness benefits, carers, volunteers and the self-employed reporting greater levels of unfair treatment.

Interestingly, having a physical disability was also associated with reporting of unfair treatment ( $p=0.030$ ) with 29 per cent [24/34] of those who had a physical disability reporting unfair treatment compared to 14 per cent [29/201] of those who did not have a physical disability.

This may be an example of multiple discrimination occurring or misattribution on the part of the perceiver as to the ground of the unfair treatment that they receive. Prevalence of unfair treatment was low in this item and, from the qualitative responses, it would appear that the problem here stems not from the attitudes of other towards people with mental health problems but, ironically, convincing others that the mental health disability exists at all. This represents a curious form of unfair treatment and again highlights some of the additional negative aspects that exist in the lives of people with mental health problems who also have other types of disabilities.

### **Item 11: Have you been treated unfairly in getting welfare benefits or disability pensions?**

Nearly a quarter (24 per cent [64/262]) of those who answered this question reported having been treated unfairly in getting welfare benefits or disability pensions. No significant relationships were observed between any of the individual factors and reports of unfair treatment.

*I had to appeal disability, the medical was horrendous, I was treated like a fraud, that I was guilty. They were unsympathetic, it was a very degrading and humiliating experience. It was terrifying and designed to make you feel ashamed.*

*I was on disability benefit for five years but when I went to apply for invalidity allowances, I was refused. Took two years to get. The reason given was "you're fit for work" which was not the case.*



Amnesty International (2010) has documented anecdotal evidence that some people with mental health problems face difficulties in accessing benefits and this research supports that evidence. This is a significant issue given that people with mental health problems constitute a large section of the population who receive benefits.

### **Item 12: Have you been treated unfairly in your religious practices?**

Twelve per cent [29/245] of those who answered this question reported having been treated unfairly in their religious practices.

*They don't take me seriously in my complaints because of my condition and psychiatric history therefore not allowing me the option to regain my place in the church.*

Having ever been admitted to hospital was associated with reporting of having been treated unfairly in their religious practices ( $p=0.0108$ ) with a higher proportion of those who had ever been hospitalised (16 per cent [27/171]) reporting they had been treated unfairly in religious practices compared to those who had never been admitted to hospital (three per cent [2/74]).

The fact that this is the item on which the least participants reported unfair treatment suggests that religious groups may represent a relatively 'safe space' for people with mental health problems.

### **Item 13: Have you been treated unfairly in your social life?**

More than a third (37 per cent [104/280]) of those who answered this question reported having been treated unfairly in their social life.

*Yes in childcare swap arrangements where by other party found out about my diagnosis, arrangements were then stopped.*

*I find I'm not invited to friends' parties, pub etc. I find out about it when people are talking about it afterwards.*

*I went into a pub and immediately was told that I couldn't be served. The bar man laughed at me. I felt humiliated as the bar was full.*

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Having been admitted to hospital ( $p=0.006$ ) and a greater number of hospitalisations were associated with higher reports of unfair treatment in social life. There were also significant associations both for having been prescribed side-effect tablets ( $p=0.015$ ) and mood stabilisers ( $p=0.017$ ) with higher reports of unfair treatment in both cases.

These findings echo the experience of unfair treatment already reported in relation to the neighbourhood, friends and family. These results suggest many participants feel isolated from the social environment because of

people's response to their mental health status. Once again these problems are more pronounced for those participants who have been hospitalised or treated with psychotropic medications.

#### **Item 14: Have you been treated unfairly by the police?**

Nearly a quarter (23 per cent [52/222]) of those who answered this question reported having been treated unfairly by the police.

*Because of the stigma they don't believe what I say. They look at the illness and the fact I was in the services for years. I tried to get a barring order [against family member], got it, it was broken but the guards didn't come.*

*Once arrested for no crime - just because I was high which was a breach of my rights.*

Having ever been admitted to hospital was significantly associated with reporting of having been treated unfairly by the police ( $p=0.0101$ ) with a higher proportion of those who had ever been hospitalised (29 per cent [45/156] reporting that they had been treated unfairly compared to those who had never been admitted to hospital (11 per cent [7/66])). There was also an effect of having been treated under the Mental Health Act ( $p<0.0001$ ) with 44 per cent [27/62] of those who had been treated under the Act reporting that they had been treated unfairly by the police compared to 16 per cent [25/160] of those who had not been treated under the Act.

*When I was being sectioned [involuntarily detained in hospital] I was handcuffed which wasn't necessary because I wasn't violent. I was just scared and frightened.*

Being prescribed anti-psychotic medication was also significantly associated with reporting of being treated unfairly by the police ( $p=0.0043$ ) with those prescribed anti-psychotic medication having a much higher level of reporting of unfair treatment (31 per cent [35/111]) compared to those who were not (15 per cent [17/111]).

Almost one quarter of this sample reported unfair treatment by the police. In part this may be explained by the role that the Gardaí play in the process of involuntary detention in Ireland and the coercive nature of this process. The Mental Health Act 2001 provides for the involvement and intervention of An Garda Síochána in specific circumstances. These relate to making an application for a person to be involuntarily admitted (Section 9), taking a person into custody when there is a serious likelihood of the person causing immediate and serious harm to himself or others (Section 12), assisting in the removal of a patient to an approved centre (Section 13) and returning an involuntary patient to an approved centre where the person was absent without leave (Section 27). For instance, in 2007 An Garda Síochána accounted for 15 per cent ( $N=235$ ) of the applications for a person to be involuntarily detained (An Garda Síochána/ Mental Health Commission, 2009). However, this is by no means the only situation in which

the Gardaí interact with people with mental health problems and qualitative responses to this question ranged across other areas such as perceived unfair arrests and not being taken seriously in making complaints to the Gardaí.

**Item 15: Have you been treated unfairly when getting help for physical health problems?**

Nearly two in five (38 per cent [102/270]) of those who answered this question reported having been treated unfairly when getting help for physical health problems.

*I had bowel problems and when the guy heard I was on antidepressants he dismissed me as having irritable bowel and passed me on to a junior doctor. It wasn't irritable bowel.*

*My mental health problem is seen as the be all and end all. Subsequently my physical health problems have been overseen/neglected.*

*Casualty were treating me well and believed me. When they asked about my medication and what I was on there was a complete change of attitude – it was as though they didn't believe me.*

Being prescribed anti-anxiety drugs was significantly associated with reporting of having been treated unfairly when getting help for physical health problems ( $p=0.0009$ ) with 47 per cent [65/137] of those prescribed anti-anxiety drugs reporting unfair treatment compared to 28 per cent [37/133] of those who were not. There was also an effect for those who had been treated under the Mental Health Act ( $p<0.0475$ ), which was also associated with higher levels of reported unfair treatment on this item.

Participants described a discernibly different approach from medical professionals towards people they know have a mental health problem. From the qualitative answers reported it is possible to infer that sometimes people with mental health problems are not treated as reliable at relating their physical symptoms, or at least their reporting is given less weight than would have been the case if they had not made healthcare professionals aware of their mental health problems. This is of note as the World Health Organization has found that people with mental health problems are at increased risk of developing significant physical health conditions, including diabetes, heart disease, stroke and respiratory disease. People with mental health problems also have a higher rate of mortality than the general population. Therefore, the WHO recommends that people with diagnosed mental health problems are routinely assessed for indicators of poor physical health (WHO/ World Organization of Family Doctors, 2008). In Ireland, the Inspector of Mental Health Services has expressed some concerns about physical health care for residents of health service community residences (Mental Health Commission, 2010).

### Item 16: Have you been treated unfairly by mental health staff?

Nearly three in five (58 per cent [163/279]) of those who answered this question reported having been treated unfairly by mental health staff.

*I was humiliated, I was disbelieved. They assaulted me because I did not want to be there and restrained me and when I questioned their authority they became obnoxious. They said we give the orders here just listen and behave.*

*Psychiatrist would not listen to me when I told him the tablet I was on was causing me distress. I [w]ent to the GP and he changed the meds and I was fine then.*

*Being given injections against my will, taking my mobile phone off me, removing clothes and expecting me to walk around in pyjamas for two to three weeks.*

*You're degraded in hospital, you're not a human. You're not given any responsibility for your recovery. Told to take this and do that. Can't question any diagnosis or tablet. Eat at this time, get up now.*

Having ever been admitted to hospital was significantly associated with reporting of having been treated unfairly by mental health staff ( $p < 0.000$ ) with a higher proportion of those who had ever been hospitalised (67 per cent [133/199]) reporting that they had been treated unfairly compared to those who had never been admitted to hospital (38 per cent [30/80]). There was also a positive correlation with having been treated under the Mental Health Act ( $p < 0.001$ ) and number of hospitalisations with the highest level of unfair treatment (80 per cent [49/61]) reported by those who had been hospitalised more than four times. Less than half (44 per cent [46/104]) of those with no history of hospitalisation reported unfair treatment.

Being prescribed anti-psychotic medication was significantly associated with reporting of being treated unfairly by mental health staff ( $p < 0.0001$ ), with those prescribed anti-psychotic medication having a much higher level of reporting of unfair treatment (71 per cent [101/143]) compared to those who were not (46 per cent [62/136]).

People admitted to hospital are more likely to report unfair treatment by mental health staff than those who have not been in hospital. The extent of this increases with higher frequency of hospital admittance and if they have been prescribed psychotropic medication. Qualitative answers give some indication of what participants mean by unfair treatment, including paternalistic or authoritarian practices, not being listened to and, in some cases, allegations of assault. While this may represent a controversial finding, it is a finding that has been replicated elsewhere (e.g. Peterson et al., 2007; Schulze, 2007).

### **Item 17: Have you been treated unfairly in your levels of privacy?**

Nearly two in five (39 per cent [108/275]) of those who answered this question reported having been treated unfairly in their levels of privacy.

*In a clinic waiting room your name being called out to see the psychiatrist.*

*When I came back out of hospital the manager in work told work personnel that I had been in hospital.*

Having ever been admitted to hospital was significantly associated with reporting of having been treated unfairly in levels of privacy ( $p < 0.0028$ ) with a higher proportion of those who had ever been hospitalised (46 per cent [87/190]) reporting that they had been treated unfairly compared to those who had never been admitted to hospital (25 per cent [21/85]). A much higher proportion of those who were prescribed medicine side-effect tablets (55 per cent [36/66]) reported being unfairly treated compared to those who were not prescribed them (34 per cent [72/209]) ( $p = 0.0036$ ).

*Other patients sharing the same room, e.g. six people, nurses open your curtains without asking, people can take your things, I can hear everything the nurses say about other patients and about myself. No privacy when being given medication at meal times.*

Reports of being treated unfairly in levels of privacy seem to occur in many environments (e.g. hospital, work, outpatient clinics). Given evidence in cycle one that participants placed a high emphasis on face management and thought carefully about disclosing their mental health problem, privacy may take on extra significance for them and having that taken away from them is potentially very disempowering. This was exacerbated in hospital settings where the reports suggest that privacy is virtually non-existent.

### **Item 18: Have you been treated unfairly in your personal safety and security?**

Forty four per cent [125/266] of those who answered this question reported having been treated unfairly in their personal safety and security.

*Being called names and jeered at by people who perceive me as an easy target - mostly strangers.*

*On a few occasions I was verbally threatened and physically attacked by neighbours. Intimidations.*

Factors associated with unfair treatment in safety and security included being prescribed mood stabilisers ( $p = 0.007$ ) and having been involuntarily detained under the Mental Health Act ( $p = 0.040$ ), where 56 per cent [40/71] of participants responded in the positive.

It has already been shown that people in this study perceived high levels of unfair treatment in social settings and among friend and neighbours. What the responses to this item reveal is the severity of some of these negative experiences. Almost half of participants report that they felt unfairly treated with regard to personal safety and security. The qualitative responses underline the depth to which negative attitudes against people with mental health problems can run, even amounting to physical assault. The findings provide evidence that people with mental health problems in Ireland can be the subject of intimidating or even violent behaviour, evidence that is supported by research elsewhere, which finds that people with mental health problems are more likely to be victims of violence than perpetrators (Hiday et al., 1999).

**Item 19: Have you been treated unfairly in starting a family or having children?**

Nearly a quarter (24 per cent [43/176]) of those who answered this question reported having been treated unfairly in starting a family or having children.

*I was totally discouraged into not having children or relationships by my psychiatrist.*

Being prescribed anti-anxiety drugs ( $p=0.023$ ) or medicine side-effect tablets ( $p=0.011$ ) was related to higher levels of reported unfair treatment. There was also an effect for length of stay in hospital ( $p=0.028$ ) with reports of unfair treatment increasing for those with more than 87 weeks hospitalisation.

Age was also a significant factor ( $p=0.0343$ ) with those over 49 years of age less likely to report they had been treated unfairly in starting a family or having children (11 per cent [6/56]), compared to those who were younger (31 per cent [37/120]).

The unfair treatment here seems to echo the data from attitudes surveys carried out in Ireland (See Change, 2010; HSE, 2007) revealing high levels of discomfort among the general public at the idea of people with mental health problems having children. This came to the fore particularly with younger people in the survey, and this again may represent a greater salience for the issue at their particular life-stage.

**Item 20: Have you been treated unfairly in your role as a parent to your children?**

Nearly half (46 per cent [56/122]) of those who answered this question reported having been treated unfairly in their role as a parent to their children.

*My wife called me a psycho - didn't want me to have much contact with the children. Because of my illness I had little contact with my first children. Social workers are very unfair to me. I have no voice.*



Significant effects were observed for being prescribed medicine side-effect tablets ( $p=0.003$ ), anti-psychotic medication ( $p=0.014$ ), having been admitted to hospital ( $p=0.008$ ), length of stay in hospital ( $p=0.021$ ) and being detained under the Mental Health Act ( $p=0.014$ ), with each linked to higher reports of unfair treatment in parenting.

It appears from this study that not only are some people with mental health problems discouraged from having children (Item 19 above), but this unfair treatment also occurs when they have had children, with almost half of those interviewed reporting unfair treatment. There was no effect identified for gender suggesting that fathers and mothers in this study experienced unfair treatment similarly, which is interesting given the dearth of literature on male experiences (Thornicroft, 2006).

### **Item 21: Have you been avoided or shunned by people who know that you have a mental health problem?**

Nearly two thirds (63 per cent [107/285]) of those who answered this question reported having been avoided or shunned by people who knew that they have a mental health problem.

*A few times when I did try to tell people I knew they didn't want to hear it. They drifted away and made themselves scarce.*

*People cross to the other side of the road to avoid talking to you because they don't know what to believe or what to say.*

*Mainly parents I would know from my children's school. Also, my own siblings and father. No telephone calls, no visiting, no invitations to visit.*

Being avoided or shunned by people who knew the participant had a mental health problem was significantly associated with having been admitted to hospital ( $p<0.000$ ), length of hospitalisation ( $p=0.002$ ) and number of hospitalisations ( $p=0.027$ ). In each case the likelihood of reporting unfair treatment increased. Also linked to higher reporting of unfair treatment was having been prescribed medicine side-effect tablets ( $p=0.005$ ) and mood stabilisers ( $p=0.004$ ).

Almost two thirds of participants in this study reported being avoided or shunned on the basis of having mental health problems. This ranged across different social groups and included family, friends and people in the community. These findings reinforce the earlier findings of rejection and unfair treatment from such groups. In a familiar pattern, people who have been hospitalised or have been prescribed side-effects tablets or mood stabilisers report consistently higher levels of unfair treatment.

### **Cumulative effect of factors increasing reports of unfair treatment**

One interesting observation across the results of the unfair treatment sub-scale (Section 1 DISC 12) was that there was a cumulative effect whereby



the more factors present for an individual, the more likely he or she was to report unfair treatment.

For example, looking at the 64 per cent who felt unfairly treated in making or keeping friend, it becomes clear that additional factors increase the proportion of participants who reported unfair treatment. A much higher proportion of those who were prescribed medicine side-effect tablets (80 per cent) felt unfairly treated than those who were not prescribed them (59 per cent). For those prescribed side-effect tablets admission to hospital was associated with increased perception of unfair treatment. Nearly all (85 per cent) of those prescribed side-effect tablets, and who had also been admitted to hospital, reported unfair treatment. Sub-dividing this group further reveals a final sub-group, where 92 per cent of those who were prescribed antidepressants, had also been admitted to hospital and were also prescribed side-effect tablets, reported unfair treatment. Those who did not have these associations were less likely to report unfair treatment.

Hospital admission (including frequency and length of stay) and medication were consistently associated with unfair treatment. Factors relating to hospital admission were significantly associated with reports of unfair treatment for 17 of the 21 sub-scale items. Associations with being prescribed medication were found for 13 of the 21 items. The effects were always negative (i.e., related to higher reported experience of unfair treatment).

### **Impact of unfair treatment**

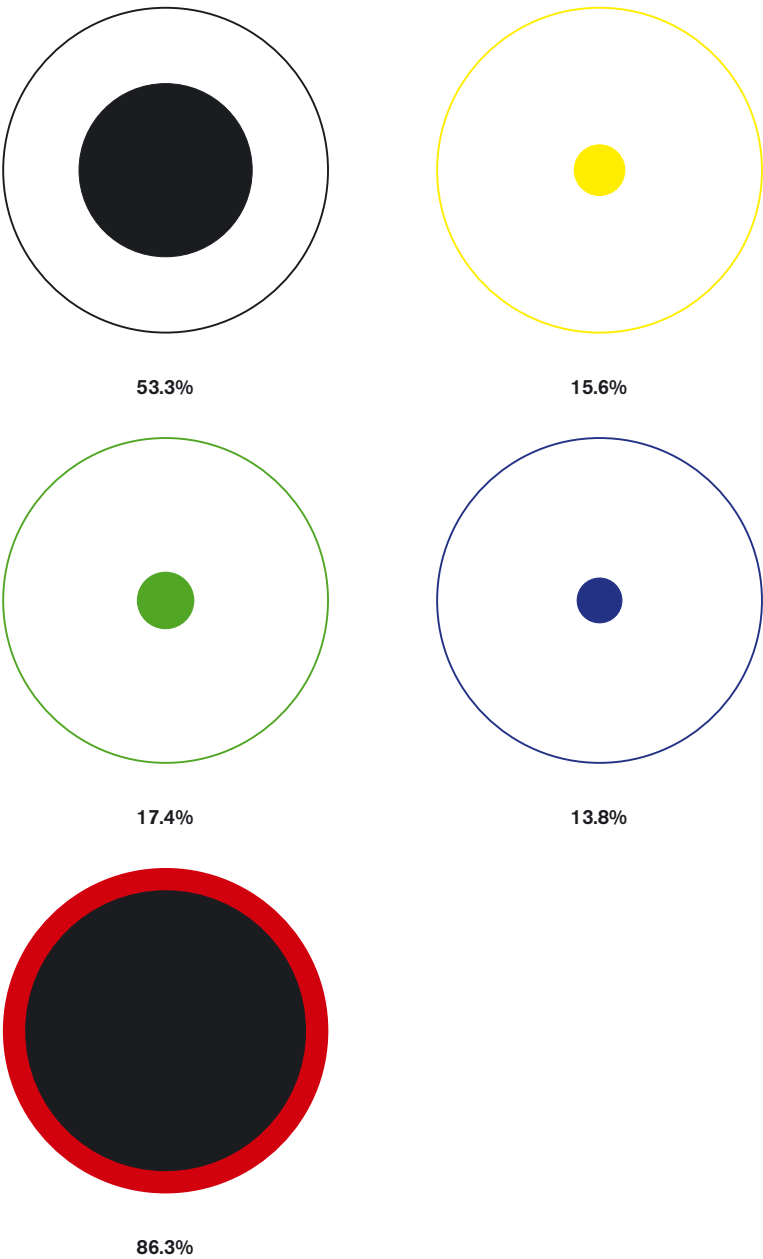
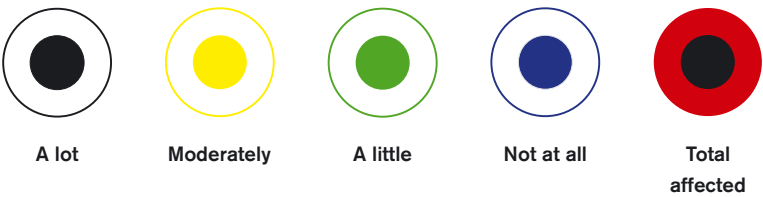
When asked whether discrimination because of their experience of mental health problems caused them distress, the vast majority of respondents (86 per cent) indicated that they experienced some level of distress as a result of discrimination (See Figure 2). More than half the participants reported experiencing 'a lot' of distress as a result of discrimination.

The Rosenberg self-esteem scale was included to examine the relationship between self-esteem and discrimination. It was hypothesised that higher levels of reported experience of unfair treatment would be associated with lower self-esteem. It has already been shown in the high level findings that self-esteem is negatively correlated with reported unfair treatment across the unfair treatment sub-scale. Strong associations were also found between lower self-esteem and participant's circumstances and reported unfair treatment. Self-esteem was significantly associated with social relationships ( $p < 0.000$ ). Those who had reported that they had been treated unfairly in making or keeping friends, or that they had been treated unfairly in their social life had a lower self-esteem than those who did not report being treated unfairly.

These findings demonstrate to some extent the impact of discrimination on participants. Nearly 70 per cent of people reported experiencing moderate or a lot of distress as a result of being discriminated against, which is highly likely to have an adverse impact on people's mental health and well-being. However, while participants with experience of unfair treatment were also more likely to have low self-esteem, the direction of this relationship is not

**Figure 2. Percentage of participants that reported experiencing distress as a result of perceived discrimination**

**Key to graph**



clear. It could be that these individuals had low self-esteem in part because of the experienced discrimination, or that people with low self-esteem were more at risk of experiencing discrimination.

### **Multiple Discrimination**

People were asked if there were any other reasons they think they may have been discriminated against, as well their mental health problems. There was a diverse range of reasons reported with some common threads. Nationality and not being from the local community was the reason stated most often (N=27), followed by appearance and way of living/being (N=18), gender (N=15) and age (N=14). Other examples of discrimination were rarely mentioned and related to sexual orientation, disability, marital status, religion, unemployment and education.

### Summary of key findings for unfair treatment

Nearly everyone who participated in the study (95.4 per cent (N=292

- reported some level of unfair treatment as a result of a mental health problem.

On average, participants reported unfair treatment in 41 per cent of the

- 21 items of the unfair treatment scale.

The five highest incidences of reported unfair treatment related to

- making or keeping friends (64 per cent); having been treated unfairly by family (61 per cent); being avoided or shunned by people who knew participants had a mental health problem (63 per cent); being treated unfairly by mental health staff (58 per cent) and being treated unfairly in your role as a parent (46 per cent).

Participants reported being treated unfairly in relation to finding a job

- (36 per cent) and keeping a job (43 per cent). When considering the examples given by people who felt treated unfairly in relation to their social life that frequently related to their work environment, the extent of unfair treatment to do with employment is further underlined.

Being hospitalised and prescribed medication was associated with

- higher reports of unfair treatment against most of the 21 items. Different types of medication affected reports of unfair treatment differently.

Wherever people reported unfair treatment there was a cumulative

- increase in reporting according to the number of factors analysed.

The more factors present, the more unfair treatment reported with the

converse also true, i.e. the fewer factors present, the less reporting of unfair treatment. The key factors influencing this cumulative effect were; hospitalisation, length of stay, involuntary detention under the Mental Health Act, having been prescribed side-effect tablets, and having been prescribed psychotropic medications such as mood stabilisers.

The majority of participants (86.2 per cent) reported experiencing

- distress due to their perception of being discriminated against because of their mental health problem. More than half the participants reported experiencing 'a lot' of distress as a result of discrimination.

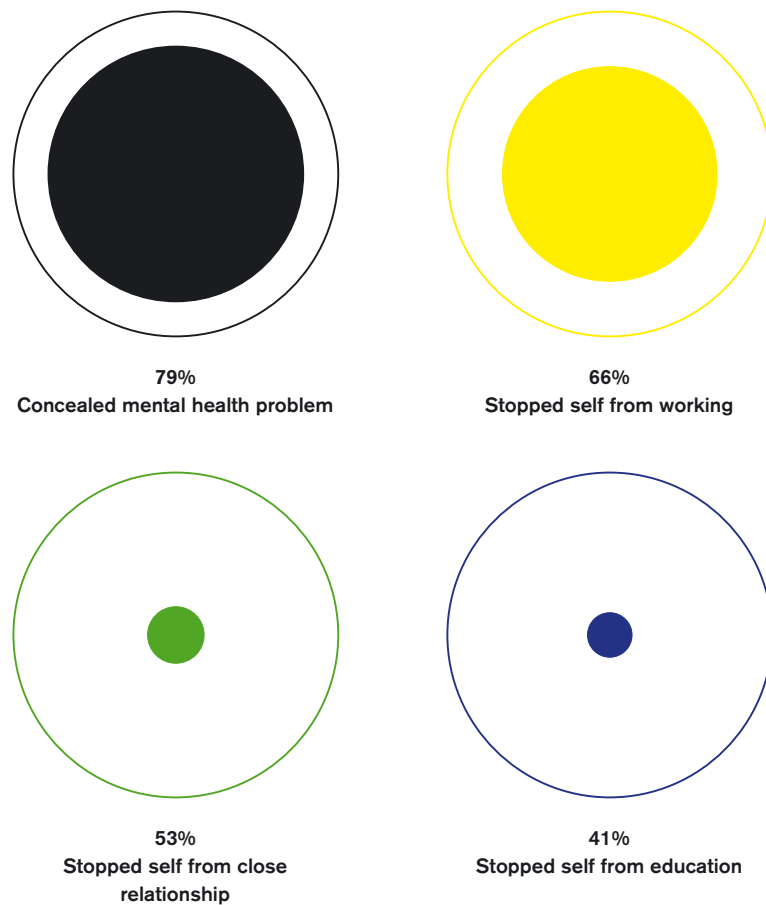
Participants with low self-esteem were more likely to report having

- experienced unfair treatment. Self-esteem was significantly associated with social relationships, with those who had reported they had been treated unfairly in making or keeping friends or in their social life, having a lower self-esteem than those who did not report being treated unfairly.

### Anticipated Discrimination

Section 2 of the DISC 12 asks participants four questions relating to times when they stopped themselves from doing things that were important to them because of how they thought others might respond to their mental health problems. This was in order to measure anticipated discrimination. On average, participants reported stopping themselves in 60 per cent of the four items of the 'anticipated discrimination' scale. Scores were negatively correlated with scores for self-esteem; that is, participants with lower self-esteem tended to stop themselves from doing things more. Figure 3 illustrates the extent that participants reported stopping themselves; and illustrative verbatim quotes provide some personal context to responses.

**Figure 3. Percentage of participants that reported anticipated discrimination**



Being prescribed anti-anxiety medication was associated with increases in the proportion of those reporting that they had stopped themselves from applying for work (76 per cent compared to 60 per cent;  $p < 0.000$ ), and applying for education (48 per cent compared to 34 per cent;  $p = 0.016$ ). This was compounded by other factors. All 28 participants who were prescribed anti-anxiety medication and had been hospitalised for more than 30 weeks reported that they stopped themselves from applying for work ( $p = 0.007$ ).

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*I have wanted to go for jobs but I have known that if they know of my mental health, they wouldn't employ me and would only see my difficulties not my capabilities.*

*[I] didn't have the confidence in [my] own ability or self esteem to go for the course.*

*I am afraid of it, how will I be seen when I say the course I want to do is counselling.*

*The services told me I wasn't able. I believed them and stopped myself applying for jobs.*

Self-esteem was significantly associated with people stopping themselves from doing things that were important to them because of how others might respond to their mental health problems ( $p < 0.000$ ). Participants who reported they had stopped themselves from applying for work or from applying for education or training courses or stopped themselves from having a close personal relationship had lower scores for self-esteem than those who did not. There was also a significant association ( $p = 0.013$ ) between self-esteem and hiding mental health problems from others. Those who had concealed or hidden their mental health problem from others had a significantly lower self-esteem score than those who did not.

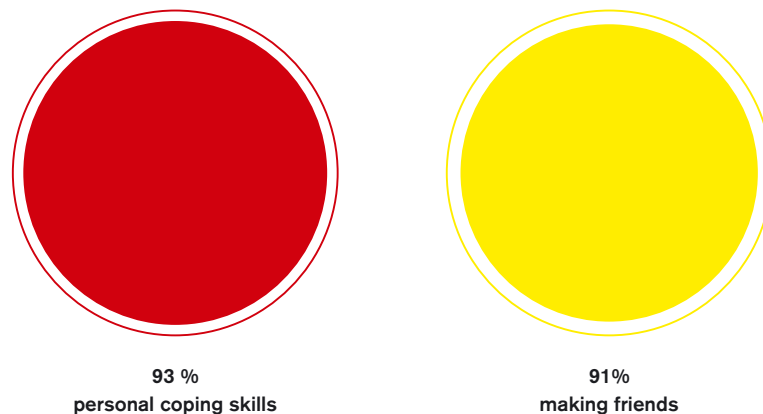
### **Summary**

- On average, participants reported stopping themselves from doing things they felt were important, because of how they thought others would respond to their mental health problems in 60 per cent of the four items of the stopping self scale
- Nearly 80 per cent of people concealed their mental health problems from others. More than 60 per cent of people stopped themselves from working. More than 50 per cent of people stopped themselves from having a close relationship. More than 40 per cent of people stopped themselves engaging in education.
- Low self-esteem was significantly associated with people stopping themselves from doing things that were important to them because of how others might respond to their mental health problems. For example, those who had concealed or hidden their mental health problem from others had a significantly lower self-esteem score than those who did not.

### **Overcoming Discrimination**

Section 3 of the DISC 12 asked participants two questions about ways in which they may have overcome discrimination. One question looked at social distance, asking whether people had overcome discrimination in social circumstances by making friends outside of mental health services. The second asked whether people used their own coping skills or abilities to overcome discrimination. Quantitative and qualitative results are summarised below.

**Figure 4. Percentage of those who reported methods to overcome discrimination**



The vast majority of participants reported using their personal coping skills with 91 per cent of participants having made friends with people who don't use mental health services and over 93 per cent of participants having been able to use their personal skills or abilities in coping with stigma and discrimination.

#### **Making friends outside of services**

*Yes I have lots of friends but I don't ask them if they have a problem so I don't know who does or who doesn't if that makes sense.*

*Most of my friends do not use mental health services.*

#### **Coping Skills**

*Deep breathing and relaxation.*

*I am not bothered any more what people think of me. I am as good as anyone else. I am more confident in myself, more accepting of myself.*

Personal circumstances were very strongly associated with the question "Have you made friends with people who don't use mental health services?" Education level had the largest individual effect, with only 72 per cent of those whose education had stopped at primary level reporting having made friends compared to 89 per cent of those who had achieved a Junior Certificate qualification or higher ( $p = 0.0381$ ). A higher percentage of those on median income or greater (€11,960) reported having made friends compared to those below median income (99 per cent compared to 90 per cent;  $p = 0.0034$ ). Employment was also associated with having friends outside of mental health services, with 100 per cent of participants who were employed in some capacity reporting having made friends outside of mental health services compared to 85 per cent of those who were not employed in some capacity ( $p = 0.0357$ ). Within the current study these



results flag the huge potential that social inclusion through education and employment may hold for people with the capacity to personally challenge discrimination.

*I am articulate and have read extensively about the politics of the service user movement and this has helped enormously.*

*I work hard at building my competency and abilities, for example, studies. I avoid places and situations where I have experienced discrimination.*

In terms of medication, the use of antidepressants increased reporting of having made friends outside of mental health services (93 per cent compared to 83 per cent;  $p = 0.0136$ ) while the use of anti-psychotics was linked to fewer friends. Physical disability and blindness were also associated with making fewer friends and using individual coping skills less, possibly suggesting it is more difficult to overcome multiple discrimination in these ways. High reports of using coping skills were linked with higher self-esteem.

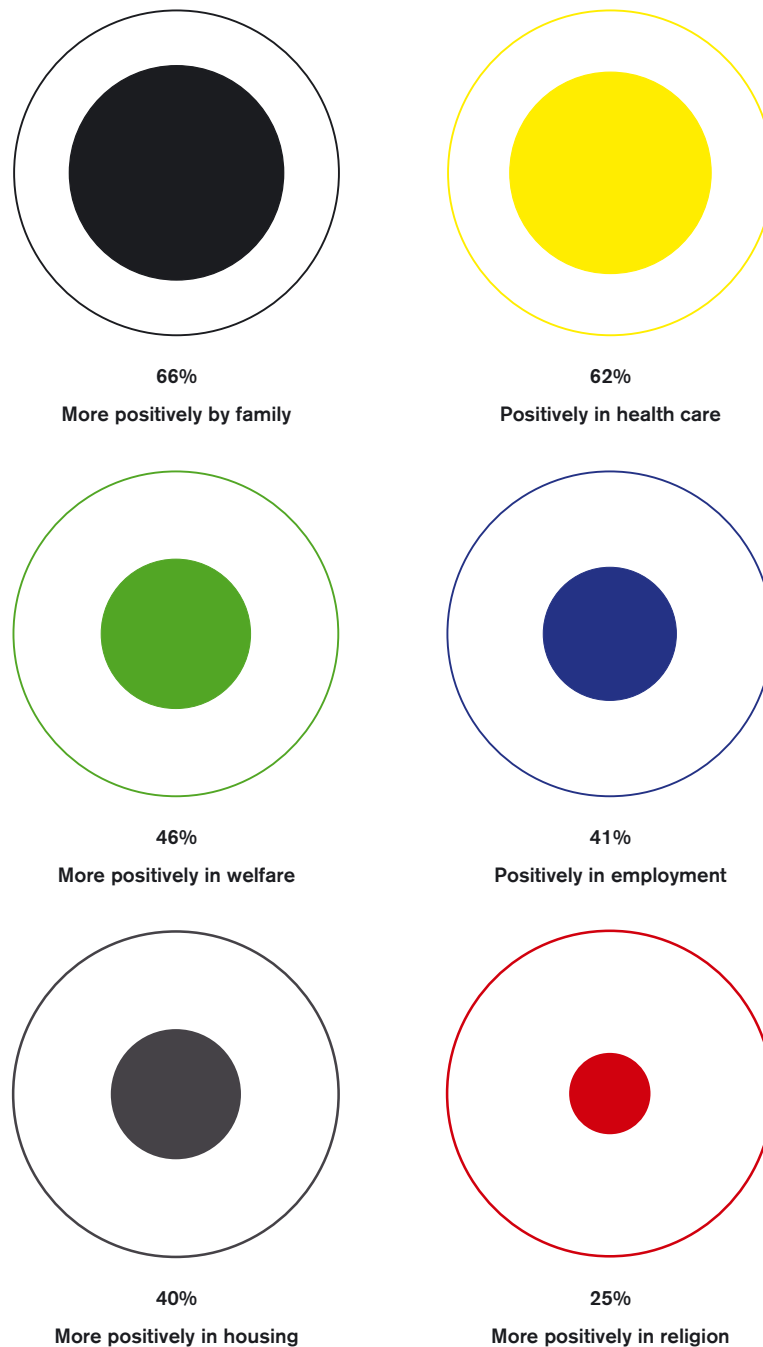
### **Summary**

- Participants in this study were observed to invest heavily in attempts to overcome discrimination, with the vast majority of respondents combating isolation and exclusion through friendships and deploying personal coping skills.
- Employment and education were associated with higher levels of friendships outside of service users, suggesting an important role for both in facilitating social inclusion and providing people with mental health problems with vital social networks. Treatment with antidepressants was also associated with making more friends.
- Being prescribed anti-psychotics and having multiple disabilities were found associated with lower reports of overcoming discrimination. Where participants reported high levels of coping skills in overcoming discrimination they scored significantly higher on self-esteem than those reporting lower levels of coping skills.

### **Positive treatment**

The final section of the DISC 12 asks participants six questions about times when they were treated more positively because of their mental health problems. On average, participants reported positive treatment in 51 per cent of the six items. Percentages for each item are summarised in Figure 5.

**Figure 5. Percentage of participants reporting experiencing positive treatment**



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For those reporting positive treatment there were a number of significant associations observed. Contrary to what was found in previous sections, participants who had been hospitalised also reported higher levels of positive treatment when compared to those who had not been admitted to hospital in the areas of family, welfare and housing.

More positive treatment by family was also found to be related to taking anti-psychotic medication, having less than the median income and being male. In all cases these people were more likely to report more positive

treatment.

Those who were employed in some capacity reported a much higher rate of positive treatment with regard to employment than those who were not employed in some capacity (75 per cent of those employed full-time in some capacity compared to 51 per cent of those employed part-time and 30 per cent of those who were not employed at all in some capacity;  $p = 0.048$ ).

*As well as being turned away for work I have also been given work because I was a service user.*

*I was working for somebody who accepted my absences due to illness and never challenged my absences and appreciated when I was there.*

*I work with a mental health group where there is an understanding of issues.*

### **Summary**

- Participants reported positive treatment on average across half of the life areas asked about in this section of the DISC 12.
- The same factors that were seen to be related to many instances of unfair treatment, e.g. hospitalisation and medication, were also related to higher reports of positive treatment, particularly by family. Being hospitalised was also associated with more positive treatment in relation to housing and welfare payments.

### **Sources of support in case of being treated unfairly**

Participants were asked who they would turn to for support or help in cases of unfair treatment. Interestingly, friends and family were mentioned most often ( $N=165$ ), despite those groups also having the highest association with unfair treatment. The second most important sources of support were health professionals and mental health services ( $N=108$ ), again, a group that featured very highly in the reports of unfair treatment. A total of 48 people mentioned peer support groups (e.g. GROW, IAN, Aware, clubhouses, other service users). Very few people ( $N=16$ ) mentioned NGOs (e.g. Samaritans, Shine, St. Vincent de Paul, CARI) and just 12 people mentioned state organisations such as the Citizens Advice Bureau or the Ombudsman, for instance. Other sporadically mentioned examples were people at work, advocates, the Gardaí and politicians. In addition, 34 people stated that they would not turn to anybody and would deal with the problem themselves or that they did not know who to turn to.

When specifically asked about any other agencies that could help in the case of unfair treatment, most people stated peer support groups ( $N=103$ ; e.g. GROW, Aware, IAN, NSUE). Less than a third of participants responded with state-led organisation, some of which have specific anti-discrimination and equality remits. ( $N=99$ ), including Gardaí ( $N=5$ ), the various Ombudsmen (6 per cent;  $N=17$ ), the Equality Authority ( $N=18$ ), or the Citizens Information Centre ( $N=46$ ). NGOs (e.g. Samaritans, Shine,

St. Vincent de Paul) were mentioned by 65 people including nine people who mentioned AI, although this may have been inflated as the study was commissioned and advertised by AI.

## Chapter 5: Discussion

### Introduction

This study sought to examine the experience of discrimination as perceived by a group of people in Ireland who have or have had mental health problems. The findings are based on participants' self reported experiences discrimination, defined as unfair treatment, obtained through semi- structured and structured interviews. Findings need to be viewed with this in mind and in the knowledge that where people are reporting discrimination, the perceptions of others, for example, alleged perpetrators of discrimination have not been elicited nor have objective third party observations of such instances been carried out. Nonetheless, the study has provided a huge volume of new and interesting information about the first hand reports of unfair treatment and discrimination from a previously understudied sector of society.

### Summary of findings

The vast majority of participants (95.4 per cent) in this study reported some experience of unfair treatment because of their mental health problems and reported experiencing unfair treatment, on average, across 40 per cent of the life domains to which they responded. The five areas in which participants reported most unfair treatment related to making or keeping friends (64 per cent); having been treated unfairly by family (61 per cent); being avoided or shunned by people who knew they had a mental health problem (63 per cent); being treated unfairly by mental health staff (58 per cent) and being treated unfairly in their role as a parent (46 per cent). Scores from the structured interviews alongside data from in-depth, semi-structured interviews also suggest that employment is a key site of perceived discrimination. In most cases, the experience of hospitalisation was associated with high levels of reported unfair treatment, while being prescribed medication was also associated with higher levels of reported unfair treatment, though in different ways depending on the questionnaire item and type of medication.

A large majority of participants reported distress (86.5 per cent) as a consequence of perceived discrimination, suggesting that the impact of discrimination is strongly negative. Furthermore, as reports of unfair treatment increased, participants' scores for self-esteem decreased and this may also evidence the impact of unfair treatment - although the relationship between the cause and effect is not clear. A similar relationship was observed between self-esteem and stopping oneself from engaging in close relationships, applying for work or pursuing education (anticipated discrimination). A high proportion of participants said they had strategies to overcome discrimination, e.g. through developing friendships and personal coping strategies. Participants also reported positive treatment across, on average, half of the items related to this topic. Friends, family and mental health staff were identified as the most likely source of support in cases of unfair treatment while peer support organisations were most commonly identified as the groups that could provide help in cases of unfair treatment. Less than a third of participants (N=99) cited public agencies as sources

of help in the case of unfair treatment and only six per cent (N=18) cited the lead anti-discrimination agency, the Equality Authority, as a source of support.

### **International comparison**

The extent of reported discrimination tended to be higher in this study than that observed in other similar studies. Compared with Thornicroft et al. (2009), which used a similar questionnaire, reports of unfair treatment were higher. For example, the number of people reporting unfair treatment in relation to 'making or keeping friends' was 64.2 per cent in the current study, compared with 47 per cent in the Thornicroft study. 'Being treated unfairly by your family' was reported by 60.8 per cent of participants in this study, compared with 43 per cent in Thornicroft's study. Corrigan et al. (2003) also reported high levels of discrimination in a USA sample of people accessing community mental health services. About 25 per cent of these reported discrimination by mental health staff compared to 58.4 per cent in the current study. Other areas, such as employment and housing were more or less the same. In New Zealand Petersen et al. (2007) had similar findings for being rejected or unfairly treated by families or friends, 59 per cent in the New Zealand study compared to 60.8 per cent in this study; unfair treatment in relation to employment was approximately a third in both studies; and 17 per cent in relation to housing compared to 26 per cent for this study. The New Zealand study differed in that it found a third of participants reported discrimination in mental health services while the current study focused specifically on mental health staff. It is not clear if 'services' in the New Zealand study related to structures or personnel, so comparison of this finding must be made with caution. Participants in this study also reported higher scores for other aspects of the DISC scale, such as anticipated discrimination when compared to Thornicroft et al. (2009). Reports on these items demonstrated between five and 10 per cent higher prevalence.

Comparisons with other studies need to be made with caution not only due to cultural differences, but also because the recruitment and sampling methods differed between studies. For instance, Thornicroft et al. (2009) specifically surveyed the experiences of people with diagnosis of schizophrenia whereas in the current study people were recruited based on self definition of a mental health problem. Given that the literature on attitudes shows more negative attitudes towards people with a diagnosis of schizophrenia than other mental health problems one may have expected levels of reported discrimination to be higher in Thornicroft's study. However, this was not the case. Also, other studies tended to focus on recruiting from populations within mental health services generally whereas this study recruited people from the community at large.

The research was explicitly advertised as research into discrimination and therefore there may have been an element of self-selection. Anecdotally, the experience of researchers in the field suggest that many participants did not assume they were participating because the study was about discrimination and it was only when the interview structures were explained and they were

asked to talk about discrimination that they consciously thought about it. That said it is possible that participants took part because they wanted to talk about their experiences of discrimination and this may account for the higher levels of reported discrimination in this study compared to some others.

### **Emergent Findings**

The current study has found evidence of high levels of perceived unfair treatment across a wide variety of social interactions for people with mental health problems. The extent of perceived unfair treatment by family, friends and community has serious implications for individuals. If these findings are interpreted along with those relating to dating/intimate relationships and being treated unfairly in social life, a picture unfolds whereby a person could potentially feel unfairly treated by their entire social network relating to all of their social interactions. It comes as little surprise then that such a high percentage of people reported stopping themselves engaging fully in various aspects of life, in the face of such widespread perceived hostility and rejection. The findings do however show that despite the extent of reported unfair treatment by family, and friends, these were the groups that participants turned to most frequently for support when they needed it. This reveals a complex picture whereby people may play both positive and negative roles in perpetuating prejudice and discrimination against people with mental health problems. In the case of familial relationships this may happen simultaneously where well-meaning and benevolent acts of care can be interpreted as paternalistic or disempowering.

In addition to the information that was sought in the research aims, a number of novel findings have emerged from the current study which merit further mention. Interesting information provided by this study relates to the association between unfair treatment in employment and factors of hospitalisation and treatment with medication. The findings have consistently shown that participants' reports of unfair treatment are likely to be higher where they have been in hospital and been prescribed psychotropic medication, for example, anti-psychotic tablets. Other related factors such as length of stay in hospital, number of admissions and if a person had been detained involuntarily, were also associated with increased reports of unfair treatment on certain items. Conversely, this cumulative effect was reversed where factors were not present, for example, where people had not been admitted to hospital or been prescribed psychotropic medication. There is some association then between the principal treatments for mental health problems that participants received and their experience of discrimination. Thornicroft et al. (2009) observed a similar trend with length of treatment and the experience of coercive treatment both related to higher levels of reported unfair treatment.

Thornicroft's study also observed that anticipated discrimination and reports of unfair treatment were related. This was repeated in the current study with those who stopped themselves from doing things due to fear of being discriminated against also more likely to report higher levels of actual unfair treatment. The causal nature of this relationship was not established but once again it shows the close relationship between anticipated and reported



discrimination. People in this study appeared to limit their lives, avoiding situations or relationships where they may be exposed to discrimination.

This study did not investigate the links between particular diagnoses and discrimination. However, the findings could indicate that individuals with more severe mental health problems that require hospitalisation are at greater risk of experiencing discrimination. Alternatively, it could indicate that greater involvement with mental health services in the form of hospitalisation itself puts a person at greater risk of discrimination. It is not possible to determine which of these interpretations is correct based on the evidence from the study. The explanation of these results is rendered more difficult by some divergent findings within the study that show positive associations between self-esteem and hospitalisation, for instance, and also between drug treatment, hospitalisation and positive treatment in some aspects of life. Further exploration of these associations is therefore required before firm conclusions are drawn about the nature of the relationships between treatment history and perceived discrimination.

Another item that emerged unexpectedly strongly from this study was the high level of experience of unfair treatment with regard to parenting and this appears to be the first finding of its kind in an Irish context. Almost half of those responding to the question felt they were treated unfairly, the fifth highest area of reported unfair treatment. A quarter of participants also felt unfairly treated in starting a family or having children, typically being strongly discouraged from doing so. Those reported to have displayed discriminatory behaviour included health professionals, social services, friends and family, and parental partners.

The treatment of parents with a mental health problem and support for childcare has received some attention in other jurisdictions, with the evidence suggesting that it is a neglected area, characterised by poor services and negative attitudes and differential treatment (az-Caneja and Johnson, 2004; Howard et al., 2004; Wang and Goldsmith, 1994; Hearle and McGrath, 2000). As Hetherington and Baistow (2001) argue, this is an issue of ever increasing salience. The process of deinstitutionalisation means that many parents are now remaining in their homes rather than being hospitalised and are therefore in a position to look after their children where previously they would not have been.

In addition to the nature and prevalence of discrimination, this research sought to add to the published knowledge on the impact of discrimination. Elsewhere self-esteem has been examined within the broader context of stigma, although a focus on actual experiences of discrimination has been lacking. It has already been shown that stigma and discrimination create an increased burden on people with mental health problems and their families, with a strong negative effect on indices of positive mental health, e.g. self-esteem (Stuart 2008). In this study it has been shown for the first time that perceived discrimination and anticipated discrimination are negatively correlated with self-esteem for a group of people with mental health problems. In addition 85 per cent of participants reported being distressed by their experiences of discrimination with more than half, 53.3 per cent, experiencing 'a lot' of distress. The impact of discrimination on individuals

suggests that discrimination is likely to perpetuate mental health problems and even prevent people from utilising the existing resources (e.g., personal supports, mental health services) to alleviate their problems. These findings resonate with the concerns expressed in A Vision for Change (Department of Health and Children, 2006) that stated stigma and discrimination can have a far greater impact on the lives of service users than their mental health problems alone and further reinforce the need for prompt and effective strategies to alleviate the negative impact of discrimination.

### **Limitations of this study**

There were some inevitable limitations of the study that need to be highlighted. The results of the study rely wholly on the self reported experiences and therefore the validity of these reports must be considered. The perception of discrimination is “a judgement that one has been treated unfairly because of his or her social group membership” (Kaiser and Major, 2006) but these judgements are inherently subjective, and can easily over or underestimate the actual occurrence of discrimination (European Commission, 2007). Reviewing the literature on this Major et al. (2002) found evidence that groups that had a past history of discrimination (e.g., women and ethnic groups) were prone to being both over-sensitive and under-sensitive in perceiving discrimination. They conclude that a complex combination of personal, situational and structural factors will influence the likelihood that an individual will see themselves as having being subject to discrimination. Such a level of detail was not elicited in the current study. This would have required detailed examination of specific instances of reported discrimination from multiple perspectives. The comparisons drawn with other studies, with the caveats discussed above, give one form of validation to the reports. In future research, experimental and observational studies could help in verifying and further explaining the accounts of discrimination given here.

It is also acknowledged that the sample used in this study was not representative nor randomly selected. Participants responding to recruitment notices would know that they were participating in the study because of their mental health problems and that the study was about discrimination which may have lead to over-reporting. This also makes cross-comparison with other data sets problematic and at most we can point to common trends and speculate that similar processes are at work where findings converge.

A further limitation that should be noted concerns the historicity of accounts provided. No attempts were made within the methodology to restrict or measure the time frame for which participants reported unfair treatment. Therefore we cannot conclude definitively from the findings to what extent reports of unfair treatment or associations with hospitalisation or medication may relate to outdated attitudes and professional standards or antiquated treatment facilities and less sophisticated drug therapy with more debilitating side effects. While this would not negate the individual experience of discriminatory behaviour, it could present a variance with contemporary experiences, particularly of service use. However, more than a third of the sample was aged under 40 years and the average age of mental health problem onset was 25 years, so their accounts are likely to be relatively recent.

## **Conclusion**

While the research is not without limitations, it evidences the perception among a large number of people with mental health problems in Ireland that they have experienced unfair treatment and discrimination on the basis of their mental health problem. It also suggests that the extent of discrimination against people with mental health problems in Ireland may be much wider than previously thought and is having a very negative impact on their ability to recover and live a full life.

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